

**LIVED EXPERIENCES OF YOUNG PEOPLE LIVING WITH MENTAL HEALTH  
CARE USERS IN LIMPOPO PROVINCE**

**By**

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**at the**

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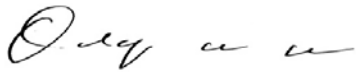
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**January 2018**

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### **DECLARATION**

I declare that **LIVED EXPERIENCES OF YOUNG PEOPLE LIVING WITH MENTAL HEALTH CARE USERS IN LIMPOPO PROVINCE** is my own work and that all sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.



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**Mamokota Maggie Molepo**

**15 January 2018**

**Date**

## DEDICATION

*I dedicate this study to my late parents, my mother Mosebjadi wa Ngwato wa Mologadi and my father More Mogolo wa Mahlako wa Hlabirwa and also to my children Jimmy, Thandi, Debora and my grandchildren Ebenezer, Orefile and Onalerena and to all young people living with mental health care users, who are faced with various challenges.*

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I would like to thank God Almighty for giving me strength to go through this study.

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To my children Jimmy, Thandi, Debora and my grandchildren Ebenezer, Orefile and Onalerena, thank you for your support and encouragement.

MAY GOD BLESS YOU ALL

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## **ABSTRACT**

The purpose of the study was to investigate the lived experiences of young people living with mental healthcare users (MHCUs) in order to gain insight into their needs and how their daily coping can be maximised. A qualitative, descriptive phenomenology study was undertaken, with face-to-face, audio-recorded individual in-depth interviews conducted with 10 participants aged between 19 and 23 years, at their homes. Participants were recruited from one of the local health clinics in Dikgale area, Limpopo province, where the MHCUs collect medication and attend follow-up medical reviews. Non-probability purposive sampling technique was used to select the sample size.

The following were the objectives of the study:

- To explore and describe the lived experiences of young people living with MHCUs.
- To determine the coping strategies of young people living with MHCUs.

Five themes and 12 sub-themes emerged from the study. The findings of the study revealed that young people were faced with psychological effects, caring demands and responsibilities, effects on their schooling performance, and lack of coping and support. The study results informed recommendations to the psychiatric nursing services on the needs and support to be provided to these young people in order to ensure maximum coping in their life situation.

### *Keywords:*

Family, Lived experience, Mental health, Mental health care users, Mental illness, Young people

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## LIST OF ABBREVIATIONS

MHCUs	Mental Health Care Users
WHO	World Health Organization
UNESCO	United Nations Educational Scientific and Cultural Organization
PHC	Primary Health Care
UNISA	University of South Africa



## **CHAPTER 1**

### **ORIENTATION OF THE STUDY**

#### **1.1 INTRODUCTION**

Global mental health reforms to improve mental health care services brought about various forms of restructuring in mental health care services. Deinstitutionalisation, as a policy strategy with the intention of using established community-based facilities for further care aimed at reducing the number of acute or sub-acute inpatient beds in psychiatric institutions, made a dramatic impact. In first-world countries that were able to ensure that it is accompanied with the establishment of community-based psychiatric units, this policy yielded noticeable success (Botha, Koen, Joska, Parker, Horn, Hering & Oosthuizen 2010:461). South Africa, as in other parts of the world, pursued deinstitutionalisation but it has been met with various challenges that had negative effects on mental health care users (MHCUs) and their families. Shortages in both human and material resources led to MHCUs' brief hospital stays, and in some instances, premature discharge to accommodate those who were more seriously ill. Inadequate community resources or the absence thereof in some cases, led to stigmatisation of patients in the community, high levels of patient abuse, homelessness, and recurrent readmissions (Botha et al 2010:461).

The MHCUs have been left with families – who are inadequately equipped – as their primary source of care (Tan, Yeoh, Choo, Huang, Ong, Ismail, Ang & Chang 2012:2411). Some of these family members are young people. Besides being exposed to living with a parent or sibling who is mentally ill, some of these young people may even be involved with care giving. With a lack of support and knowledge about the nature and treatment of mental illness at home, the consequences are that MHCUs are frequently readmitted to hospital after remaining well for a short period; a concept called “revolving door syndrome” (Botha et al 2010:462).

It could be challenging for a young person to live with a MHCU at this critical period in their development, due to his/her inexperience and the need to concentrate on other developmental issues such as dating and the formation of friends. Caring for MHCUs

may lead to role confusion as he/she is expected to carry out adult roles (Venkatesh, Andrews, Parsekar, Singh & Menon 2016:23).

## **1.2 BACKGROUND TO THE RESEARCH PROBLEM**

Research has widely shown that having a family member diagnosed with a psychiatric illness is a risk factor for poor family functioning. Studies on the experiences of family members caring for MHCUs by Magadla and Magadla (2014:129) and Mavundla, Toth and Mphelane (2009:358), reveal adverse effects in physical, social and psychological aspects of the family. The family is required to reorganise their household routines, often with detrimental effects on their finances, social relationships, and leisure opportunities. The situation becomes chaotic for children who also suffer stigmatisation as they are perceived as having lower social, psychological, and physical health by children who come from families not affected by mental illness (Magadla & Magadla 2014:130).

Rose and Cohen (2010:474) define a young carer as a young person aged 5 to 25 years whose life is affected by the illness or disability of someone in his or her family. This young person may also be involved in providing physical and/or emotional support for that person. The likelihood that mental illness adversely affects the functioning of young people is evidenced by some experiencing guilt, interpersonal difficulties, and attachment problems. These aspects may lead to young carers experiencing various adverse outcomes in their academic performance at school, and general success in life (Mechling 2011:28; Homlong, Rosvold, Sagatun, Wentzel-Larsen & Haavet 2015:9; Reupert & Maybery 2010:631; Rose & Cohen 2010:473). Despite the vast international empirical work on young carers living with MHCUs, the need for an in-depth understanding of the experiences of young people living with MHCUs within the South African context remains essential.

## **1.3 RESEARCH PROBLEM**

Mental illness impacts on more than just the diagnosed individual; it affects all family members (Reupert & Maybery 2010:631). When a parent has a mental illness, the impact of illness is felt by all other family members, particularly his or her children.

Psychiatric care institutions have not adequately paid attention to the vulnerability of children and young people living with MHCUs, as much focus has been on supporting the adult family caregiver. The researcher, as a psychiatric nurse working in one of the primary health care centres at Dikgale area in Limpopo province, has been dealing with MHCUs on an outpatient level. Most of these MHCUs' children accompany them for reviews and follow-up treatment. The researcher observed a lot of anxiety, stress and uncertainty among these accompanists. Young people who are supposed to be at school miss classes, which could have negative outcomes on their academic performance.

The preliminary literature reviews of Bjorgvinsdottir and Halldorsdottir (2014:38), Reupert, Maybery and Kowalenko (2012:9), and Leahy (2015:101), affirm the impact that living with a mentally ill family member has on the young person's coping, lifestyle, and growth. The authors also agree that too little is known about how psychiatric care units respond to the needs of these young carers. Based on this premise, the researcher sought to investigate and understand how young people aged 18-24years experience their daily life situation in a family with a MHCU at Dikgale area Limpopo province, in order to provide recommendations on how they could be supported to improve their quality of life.

#### **1.4 RESEARCH PURPOSE**

In this study, the researcher sought to investigate the lived experiences of young people living with MHCUs at Dikgale area, Limpopo province in order to gain insight into their needs and how their daily coping can be maximised.

#### **1.5 RESEARCH OBJECTIVES**

The following objectives were formulated to attain the purpose of the study:

- to explore and describe the lived experiences of young people living with MHCUs;
- to determine the coping strategies of young people living with MHCUs; and

- to make recommendations for mechanisms to support young people living with MHCUs.

## **1.6 DEFINITION OF KEY CONCEPTS**

### **1.6.1 Experience**

Experience refers to feelings, thoughts, and knowledge gained by being involved in situations or life circumstances (Oxford Advanced Learner's Dictionary 2010:510). In this study, this refers to the experiences of young people living with MHCUs.

### **1.6.2 Family**

According to Townsend (2015:904), family means two or more individuals who depend on one another for emotional, physical, and economic support. In this study, family means a support system (a spouse, children, family, or relative of MHCUs) that provides shelter, as well as emotional, physical, psychological, and social care for the MHCU on a daily basis.

### **1.6.3 Mental health care user**

A mental health care user (MHCU) is a person receiving care, treatment and rehabilitation services, or using a health service at a health establishment aimed at enhancing the mental health status of the MHCU (Mental Health Care Act 17 of 2002:5). In this study, the MHCU will be a family member – either parent, aunt, uncle or even sibling – who has been diagnosed with a mental illness and who receives psychiatric treatment, living with an adolescent aged between 18-24 years.

### **1.6.4 Mental health status**

According to the Mental Health Care Act 17 (2002:6), mental health status means the level of an individual's psychological well-being as affected by physical, social and psychological factors, and which may result in a psychiatric diagnosis.

### **1.6.5 Mental illness**

Mental illness refers to the positive diagnosis of a mental health-related illnesses in terms of accepted diagnostic criteria made by a mental health care practitioner authorised to do so (Mental Health Care Act 17 of 2002).

### **1.6.6 Young people**

Young people refer to individuals between the ages of 15-24years (UNESCO 2015:1), sometimes referred to as an adolescent. In this study, the term 'Young people' will be used interchangeably with adolescents to mean individuals between the ages of 18-24 years, who are living with MHCUs.

## **1.7 FOUNDATION OF THE STUDY**

### **1.7.1 Paradigm perspective of the study**

This study was conducted guided by a constructivist paradigm, also called a naturalistic paradigm. A paradigm or a worldview is a way of looking at natural phenomena that encompass a set of philosophical assumptions and that guides one's approach to inquiry (Polity& Beck 2014:387). The constructivist paradigm guided the researcher on the type of methodology and research design that was used in the study. Furthermore, it assisted the researcher to focus on understanding the lived experiences of the young people living MHCUs, through the careful collection and analysis of qualitative materials that are narrative and subjective (Polit & Beck 2014:9). According to Munhall (2012:250), Mills and Birks (2014:22), and Polit and Beck (2012:13), constructivists believe that reality is multiple and subjective, mentally constructed by individuals, simultaneously shaping, not cause and effect. The constructivist paradigm assisted the researcher to obtain rich, in-depth data to clarify the different dimensions of lived experiences of young people living with MHCUs.

Constructivists use the environment where the participants live, such as their homes, to collect data (Polit & Beck 2012:14). Qualitative researchers seek to understand the context or setting of the participants by personally visiting this setting to collect and



interpret data (Creswell 2014:9). The goal of constructivist study is to rely as much as possible on the participants' views of the phenomenon being studied (Creswell 2014:8). In this study, the researcher used the constructivist paradigm because it emphasises dynamic, holistic and individual aspects in their entirety, within the context of those who are experiencing them (Polit & Beck 2012:14; Moule & Goodman 2014:209; Streubert & Carpenter 2011:88). This paradigm assisted the researcher to explore and describe the lived experiences of young people living with MHCUs.

The researcher purposively chose participants with knowledge about the phenomenon under study. Therefore, young people between the ages of 18-24 years living with MHCUs were purposively selected for the study. In constructivist paradigms, human beings are used as data collecting instruments and data collection and analysis takes place simultaneously. In this study, the findings were grounded in the real-life experiences of young people with first-hand knowledge of living daily with MHCUs. Authors such as Polit and Beck (2014:8), assume that knowledge is maximised when the distance between the researcher and the participants in the study is minimised. To that aim, in this study a small number of participants were used. The researcher put aside and wrote down all her pre-conceived ideas about the lived experience of young people living with MHCUs in a reflexive journal in order to enter participants' homes with a clean and open mind to avoid biases. The researcher collected data until there was no new information, and themes were repeating.

The constructivist paradigm assisted the researcher to gain insight into the lived experiences and the needs of young people living with MHCUs. Furthermore, using broad or general open-ended questions enabled the researcher to listen carefully to what young people living with MHCUs said or did in their life setting (Creswell 2014:8).

## **1.8 RESEARCH DESIGN AND METHOD**

In this study, a descriptive phenomenological research design using a qualitative research method was used. Polit and Beck (2012:495), Creswell (2014:245), and Brink, Van der Walt and Van Ransburg (2012:121) agree that phenomenological studies describe ordinary conscious human experiences of everyday life. Descriptive

phenomenology thus entails describing an experience as it is lived by the participants. This design assisted the researcher to explore and describe the lived experiences of young people living with MHCUs. The detailed description is provided in Chapter 3 of this study.

## **1.9 SCOPE OF THE STUDY**

This study only covered young people living with MHCUs at Dikgale area Limpopo province. Young people living with MHCUs at nearby villages were not included in the study, thus limiting generalisation of the study findings. The focus was only on young people aged between 18-24 years living with MHCUs at Dikgale area, and a small sample of these young people were used in the study. This offered a limited view of a larger population and those below this age group.

## **1.10 ETHICAL CONSIDERATION**

Ethics is a system of moral values that is concerned with the degree to which research procedures adhere to professional, legal, and social obligations to the study participants (Polit & Beck 2012:727). The ethical principles discussed in the following section were used to ensure freedom of participation, prevention of harm, and maintaining privacy through anonymity and confidentiality of the participants. These principles were central to the ethical positioning of the study.

### **1.10.1 Right to voluntary participation**

According to Brink et al (2012:38), the ethical principle of voluntary participation and protecting the participants from harm are formalised in the concept of informed consent. Informed consent comprises of three major elements that include the type of information, degree of understanding, and the fact that the participant has a choice whether or not to give consent (Brink et al 2012:38). In this study, young people living with MHCUs were requested to voluntarily be part of the study and indicate that by signing written consent to participate in the study.

### **1.10.2 Free from harm**

Even after careful consideration on the part of the researcher, sometimes interacting with participants during interviews may unintentionally cause them emotional harm. As part of the ethical consideration to ensure no harm occurs to participants, the interaction with participants (data collection) were postponed until ethical approval from the institutions of study was sought. UNISA, the Department of Health Studies, and the Higher Degrees Committee, also assessed and ascertained through the informed consent and detailed research design that no potential risk would be incurred by participants.

### **1.10.3 Anonymity and confidentiality**

Any records from the study will be kept confidential to the extent possible by law. The records were reviewed by people responsible for making sure that the study is done correctly, including members of the research ethics committee at UNISA. A code number was used to refer to any of the records of participants' information that were retained within the study. When the study findings are published, care will be taken that reporting does not in any manner specifically identify participants' involvement in the study.

Detailed discussion of ethical principles is provided in Chapter 3 of the study.

## **1.11 SIGNIFICANCE OF THE STUDY**

The study findings on the lived experiences of young people living with MHCUs informed recommendations for the psychiatric nursing services on the needs and support to be provided to these young people living with MHCUs in order to ensure maximum coping in their life situation. These recommendations may also impact on the programmes used to prepare families and MHCUs for discharge, with special focus on the young people living with MHCUs.

## **1.12 STRUCTURE OF THE THESIS**

### **Chapter 1: Orientation of the study**

Chapter 1 offers the orientation of the study, which entails introducing the study, and providing the background to the research problem. The research problem, research purpose, research objectives, the significance of the study, definitions of the key concepts, the foundation of the study, a brief discussion of the research design and method, the scope of the study, and ethical consideration are also discussed.

### **Chapter 2: Literature review**

In Chapter 2 the researcher evaluates, organises and synthesises the literature review guided by the key words.

### **Chapter 3: Research design and method**

The research design and method is described in detail in Chapter 3. It entails the research objectives, research design, study setting, research methodology, data collection, and data analysis. Trustworthiness and ethical considerations are also discussed.

### **Chapter 4: Data management, analyses and interpretation**

In Chapter 4 the researcher analyses data and discusses the research findings.

### **Chapter 5: Conclusions and recommendations**

The researcher gives conclusions for the study and makes recommendations for future research in Chapter 5.

## **1.13 CONCLUSION**

This chapter presented the orientation of the study. The introduction and background to the research problem, the research purpose, research objectives, significance of the study, and definitions of key concepts were also discussed. The foundation of the study, the research design and method, and ethical consideration

were briefly presented, as well as the structure of the dissertation. In the next chapter, the literature review is presented.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

In this chapter, theoretical and empirical literature that exists with regard to mental illness and experiences of living with MHCUs in the community is explored. According to Grove, Gray and Burns (2015:506), a literature review is a review undertaken to generate a picture of what is known and not known about a particular problem. In this study, the literature review serves to expand the researcher's understanding of the phenomenon from multiple perspectives, and this may include an examination of artistic sources in which the phenomenon is described (Polit & Beck 2012:94 & Parahoo 2014:115). Literature reviews determine gaps, consistencies, and inconsistencies in the literature about a subject, concept, or problem (LoBiondo-Wood & Haber 2014:51). It provides a framework for establishing the importance of the study, as well as a benchmark for comparing the results with other findings (Creswell 2014:28). The researcher in this study aimed to investigate the lived experiences of young people living with MCHUs in order to gain insight into their needs and how their daily coping can be maximised.

For the purpose of this study, the researcher's literature review was guided by the following aspects:

- Mental health and mental illness
- Health systems and care of MHCUs
- Policy frameworks in the care of MHCUs at home
- Mental illness and family
- Community care of MHCUs
- Young people in the care of MHCUs

With the guided help of the librarian, the following databases were used in the literature review search: Sabinet, Science Direct, Google Scholar, and Ebscohost. These databases were searched using the abovementioned key aspects.

## **2.2 MENTAL HEALTH AND MENTAL ILLNESS**

The Mental Health Act 17 (2002:6) describes mental health as the level of mental well-being of an individual affected by physical, social and psychological factors which may result in a psychiatric diagnosis. Mental illness means a positive diagnosis of a mental-related illness in terms of accepted diagnostic criteria made by a mental health practitioner authorised to make such diagnosis. According to Mackenzie (2014:6), mental illness is the suffering, disability or morbidity caused by psychiatric, neurological and substance use disorders, arising from the genetic, biological and psychological make-up of individuals, as well as adverse social or environmental factors.

Mental illness sometimes progresses to be a chronic condition that needs lifelong treatment using psychiatric drugs. According to the WHO (2013:1), mental disorders are among the top public health challenges in the WHO European Region, affecting about 25% of the population every year. Furthermore, a person with mental illness may experience episodes of mentally ill-health, which interrupt that person's capacity to fulfill their work, family, social, academic and community roles (WHO 2013:12). It has been affirmed by Verrocchio, Ambrosini and Fulcheri (2013:406) that mental disorders presenting in all age groups are associated with a number of difficulties relating to activities of daily living, work, interpersonal and family relationships, and lead to high social and economic costs. Hence, this study aimed to explore how young people within the family experience living with MHCUs.

## **2.3 HEALTH SYSTEMS AND CARE OF MHCUs**

### **2.3.1 International Health systems and the care of MHCUs**

Mental health reforms have led to various forms of restructuring mental health services worldwide. Many countries now aim to establish mental health services that are local

and community-based, organised around the needs of a population catchment area (WHO 2013:8). Various mental health policy guidelines emerged internationally and in South Africa with the aim to promote the health care of MHCUs. Due to mental health policy changes, much of the treatment of MHCUs has shifted to the community and the family, and children now play a role in providing complex care (Verrochio et al 2013:407). Internationally and nationally community-based psychiatry was successfully established. However, there were some weaknesses globally and in South Africa due to shortages of human and material resources. Still, mental health services are now accessible at the local clinics of Limpopo province, and MHCUs are in the care of their family members after being discharged from the hospital.

#### **2.3.1.1 Integrating mental health services into Primary Health Care**

According to the WHO (2007:2), integration of mental health services into primary health care has been one of the vehicles towards improving mental health care and aims:

- to reduce stigma for MHCUs and their families, and to interconnect the mental and physical health problems;
- to improve access to mental health services, and promote respect for the human rights of MHCUs;
- to provide affordable and cost-effective mental health services;
- to close the treatment gap for mental disorders and to relieve the burden of mental disorders from MHCUs and their families (WHO 2007:2).

There was success in the integration of mental health services into primary health care, and mental health and physical health became interconnected. Mental health services are accessible to MHCUs. However, the burden of care on the family living with MHCUs is still a challenge worldwide.

### **2.3.2 Health systems in South Africa and care of MHCUs**

In post-apartheid South Africa, there has been clear awareness that mental health has been neglected and that the transition to democracy requires paying much more attention to it (Stein 2014:115). According to Marais and Petersen (2015:12), integrating mental health into primary health care services may have the potential to reduce stigma because MHCUs will be treated like any other chronic patient at the clinic.

South African's health system consists of the public sector, the private sector, and Non-Governmental Organisations. The National Health Systems were established in South Africa with the aims to improve health services, to protect, respect, promote and fulfill the rights of vulnerable groups such as women, children, older persons and people with disabilities. The primary health care approach was adopted from the National Health System, which is centered on the individual, family, and community.

The White Paper for the transformation of the health systems in South Africa set out the provisions of a new mental health system, based on primary health care principles. According to the South African Department of Health, comprehensive and community-based mental health care should be planned and coordinated at the national, provincial, district, and community levels, and integrated with other health services.

This transformation assisted MHCUs and their families to easily access the mental health services closer to their homes at the local clinics because in the past they were traveling long distances to the hospital for psychiatric services. Mental health services are now also free in South Africa. However, deinstitutionalisation resulted in MHCUs living with their families in the community, and caring for MHCUs became the responsibility of their families and the community (Engelbrecht & Kasiram 2012:441).

In South Africa, regardless of this integration of mental health services in the health system, mental illness is still a challenge. MHCUs and their families still face stigma and discrimination, and the care of MHCUs is still a burden on their families. Nevertheless, access to health care services and the treatment gap has improved.



## **2.4 LEGAL AND POLICY FRAMEWORKS IN THE MENTAL HEALTH CARE**

### **2.4.1 The European Mental Health Action Plan 2013-2020**

The aim of the plan was to improve the mental well-being of the population and reduce the caring burden of mental illness, for example, the financial burden. The plan was also aimed at respecting the rights of MHCUs, addressing the stigma and discrimination related to mental illness, and establishing accessible, safe and effective services that meet people's mental, physical and social needs, and the expectations of MHCUs and their families (WHO Europe 2013:3).

The plan has been shown to be a success because MHCUs are now able to access psychiatric services at their local primary health care services and they are provided with social welfare benefits to relieve them from their financial burden. The rights of the MHCUs are seen to be respected because they can now continue receiving care and treatment at local primary health care services after being discharged from psychiatric hospitals. However, globally there are still some challenges, such as MHCUs still being discriminated against and excluded from employment.

### **2.4.2 The legal framework of mental health care services in South Africa**

#### **2.4.2.1 The National Policy Guidelines for improved mental health in South Africa 1997**

The aims of the guidelines were to develop community mental health services, downsize large mental hospitals, and develop a mental health component in primary health care and human resources. The guidelines also intend to involve users and families, advocate for MHCUs and promote health, protect the human rights of MHCUs, enhance equity of access to mental health services across different groups, and provide financing, quality improvement and monitoring systems (WHO 2007:7).

Living with MHCUs has been identified as a challenge in South Africa, and young people in these environments face demanding responsibilities and an enormous amount of stress. However, the guidelines are working well because the MHCUs are

able to get free treatment at their local community mental health services and social grants are provided.

#### **2.4.2.2 Mental Health Care Act 17 of 2002**

The Mental Health Care Act of 2002 improves access to mental health care for MHCUs, promotes the integration of mental health care into general health services, and assists in the development of community-based services. The Act also promotes the rights of MHCUs(Mental Health Care Act 17 of 2002:7).

Psychiatric services are now accessible for the MHCUs at their local clinics since mental health services are now integrated into the general health services. MHCUs attend reviews, collect follow-up treatment and consult at the local clinics. Mental illness is treated like any other chronic condition at the clinic. The promotion of the integration of mental health care into general health services and the development of community-based services is perceived to be a success.

#### **2.4.2.3 Mental Health Policy Guidelines about child and adolescents**

These policy guidelines serve as a framework for establishing mental health care services for children and adolescents at national, provincial and local levels of health care within the primary health care approach.

The policy guidelines aimed to provide a safe and supportive external environment, to build skills and offer information, counseling, and accessibility to health care services for children and adolescents(Department of Health 2001:44).

Weaknesses have been experienced relating to the care of the MHCUs because young people living with MHCUs seem to lack knowledge and skills with regard to the nature of mental illness, and they care for their parents or relative without support and counselling from professionals. However, the policy guidelines have been shown to be a success because the mental health care services are accessible to young people.

#### **2.4.2.4 The Constitution of the Republic of South Africa 1996**

Section 28 of the Constitution (1996:11) indicates that every child has the right to family care or parental care, or to appropriate alternative care when removed from the family environment; to basic nutrition, shelter, basic health care services and social services; to be protected from maltreatment, neglect, abuse or degradation; not to be required or permitted to perform work or provide services that place at risk the child's well-being, education, physical or mental health or spiritual moral or social development.

There are some flaws in the Constitution because stigma and discrimination of mental illness is still a challenge in South Africa. Young people living with MHCUs seem to be faced with neglect, abuse, and degradation. This argument is supported by Iseselo, Kajula and Yahya-Malima (2016:8), who highlight negative attitudes of people around families living with MHCUs. Young people seem not to receive proper parental care; instead, they are the ones providing care to the MHCUs. They are carrying out adult roles while they are still children themselves, and are still developing. Similarly, Leahy (2015:23) believes that growing up with a mentally ill parent exposes young people to distress and burden, affecting their level of concentration and performance at school. This can also lead to social isolation.

The physical, mental or social development of young people may be affected due to their situation of living with a MHCU parent or family member.

### **2.5 MENTAL ILLNESS AND FAMILY**

According to Malhotra (2016:109), the occurrence of mental illness in the family is perceived as trauma. Also, Sanders, Szymanski and Fiori (2014:257) view mental illness in the family as a powerful environmental change. Sporer and Toller (2017:98) highlight that mental illness disrupts family functioning and relationships. Most family members do not have adequate knowledge with regard to mental illness. This argument is supported by Shamsaei, Cheraghi and Esmaeilli (2015:1), who affirm that families generally have little prior knowledge of mental illness. Furthermore, Iseselo et al (2016:2) assert that most family members view mental illness not as a disease, but as a curse and a product of both witchcraft and evil spirits.

Mental illness can be disabling and can also affect MHCUs' functionality in different domains of life. Care is thus often required of their family members (Chang, Zhang, Jeyagurunathan, Lau, Sagayadevan, Chong & Subramaniam 2016:2).

The family is the primary resource of the MHCUs, and they act as caregivers. Furthermore, care giving in the African context is usually a family affair with multiple caregivers (Uys & Middleton 2014:88). MHCUs are now under the care of their families after they are discharged from the hospital and referred to their local clinics. Kontio, Lantta, Anttila, Kauppi and Välimäki (2017:63) assert that the burden of care remains heavy and the responsibility to support MHCUs' well-being is resumed by family members. Numerous authors believe that mental illness has an impact on the individual and their family across all domains of life (Bland & Foster 2012:518; Azman, Singh & Sulaiman 2017:98; Townsend 2015:817; Bessa & Weidman 2013:64). Furthermore, mental illness creates a considerable personal burden for MHCUs and their families, and produce substantial economic and social hardships that affect communities as a whole (Clarke 2016:498). Additionally, Weimand, Hall-Lord, Sällström and Hedelin (2013:103) state that being a family member of a MHCU could lead to anxiety and depression.

## **2.6 COMMUNITY CARE OF MHCUs**

MHCUs are discharged from psychiatric hospitals and referred to clinics in the community to continue with treatment and care. Yet, communities seem to lack knowledge with regard to the nature of mental illness and this leads to the inappropriate care and treatment of the MHCUs and their families by community members. Numerous studies identified a lack of knowledge about mental illness from the families and the community (Tlhowe, Du Plessis & Koen 2017:31; Koschorke et al 2017:72; Mizuno, Takataya, Kamizawa, Sakai & Yamazaki 2013:75; Pusey-Murray & Miller 2013:116; Sewilam, Watson, Kassem, Clifton, Mc Donald, Lipski, Deshpande, Mansour & Nimgaonkar 2015:272; Iseselo et al 2016:9 & Lippi 2016:2). The study of Venkatesh et al (2016:25) affirm that perceptions of families living with MHCUs were characterised by the stigmatising attitudes of their society. Families and MHCUs were faced with blaming, rejection and devaluing by community members (Karnieli-Miller,

Perlick, Nelson, Mattias, Corrigan & Roe 2013:256). Furthermore, Karnieli-Miller et al (2013:257) assert that in their study, some neighbours were refusing that their children play with the children of MHCUs. The families were blamed for MHCUs' diagnosis and behaviour. Additionally, it was found that the families resorted to keeping the MHCUs' diagnosis a secret, fearing rejection and discrimination (Muralidharan, Lucksted, Medoff, Fang & Dixon 2016:491). Furthermore, Rogers, Stanford and Garland (2012:308) and Engelbrecht and Kasiram (2012:443) affirm that the families were reluctant to talk about their struggles with their mentally ill family member because they were afraid to be judged. According to Venkatesh et al (2016:26), the community should support the MHCUs and their families, rather than stigmatising them. Huang, Jen and Lien (2016:4) highlight the need for anti-stigma programmes to reduce discrimination towards MHCUs.

Koschorke et al (2017:71) claim that their findings revealed that the community members stopped visiting the families living with MHCUs, and did not invite them to community functions, or stopped talking to them altogether because of the behavioural manifestations of the MHCUs. Moreover, these harmful attitudes may lead to MHCUs and their family not seeking help when they are in need, for fear of facing negative reactions. It seems as though the community is not providing support to MHCUs and their families. According to Sewilam et al (2015:116), social support is not only the responsibility of the family, but also of friends, neighbours and the entire community.

Numerous studies highlighted a need for mental awareness among the community as a whole, and at schools for young people, in order to fight against stigma and discrimination of mental illness (Sewilam et al 2015:117; Koschorke et al 2017:75 & Chang et al 2016:6).

## **2.7 YOUNG PEOPLE IN THE CARE OF MHCUs**

Parental mental illness represents a significant risk factor to the young people's well-being (Reupert & Maybery 2016:102). According to Ola, Suren and Ani (2015:74), mental illness has been shown to affect attachment formation and cognitive, emotional,

social, behavioural and physical development of young people. Lauritzen, Reedtz, Van Doesum and Martinussen (2015:864) affirm that young people in the care of MHCUs are at risk of developing mental health problems themselves. Young people who are caring for MHCUs lack emotional involvement with their parents. Abram and Stein (2013:601) believe that affection is an interpersonal bond and a sense of closeness and intimacy, and Reupert et al (2012:8) found that young people with a high functioning parent will be exposed to fewer interpersonal risks.

Young people in the care of MHCUs seem to lack support from their community and professionals because their parents or relatives are mentally ill (Radfar, Ahmadi & Fallachi-Khoshknap 2013:4; Trondsen 2012:182; Pusey-Murray & Miller 2013:118). Trondsen's (2012:181) study revealed that a MHCU parent was incapable of performing their parental role and was unable to assist young people with their school work or leisure activities. They also failed to be attentive in conversation. Furthermore, Van Loon, Van de Ven, Van Doesum, Witteman and Hosman (2014:1210) believe that mental illness might impair parents' capacity to supervise the behaviour of their children.

According to Trondsen (2012:178), young people lack information and openness in the care of MHCUs. Brook-Sumner, Lund and Peterson (2014:3) affirm that family caregivers, in general, lack knowledge with regard to the diagnosis of mental illness and its causes. This lack of knowledge and information often lead to uncertainty and fear among young people living with MHCUs of losing their mentally ill parent (Winther-Lindqvist 2014:95).

Young people in the care of MHCUs seem to face the hard work and total adjustment to the MHCUs' condition 24 hours a day because the MHCU is dependent and unable to take responsibility regarding everyday life (Rossen, Stenager & Buus 2014:456). Young people may also assume inappropriate levels of responsibility in caring for themselves, their siblings, the mentally ill family member, and their household (Leahy 2015:101 & Sanders et al 2014:260). According to Sanders et al (2014:258), young people in the care of MHCUs neglected their own needs because of their tremendous responsibility. Townsend (2015:817) asserts that providing care 7 days-a-week, 24-hours a day can be very exhausting and frustrating. Additionally, Trondsen (2012:181)

found that young people in the care of MHCUs described themselves as an extra adult in the family, especially during their parent's bad periods.

Cooklin (2013:229) and Homlong et al (2015:9) highlight that young people in the care of MHCUs are faced with physical problems, neuropsychological development, emotional and educational problems, and may even suffer from stigma by association with the parent who is a MHCU. Foster, O'Brien and Korhonen (2012:9) affirm that there is evidence across several decades of the potential for negative impacts on young people and families with parental mental illness who do not have adequate psychosocial support.

Various studies stress the need for support and education among young people in the care of MHCUs about mental illness (Foster et al 2012:8; Reupert et al 2012:9; Trondsen 2012:185; Ola et al 2015:77; Homlong et al 2015:9; Van Loon et al 2014:1211).

The health systems as well as policy frameworks, internationally and in South Africa, aimed to develop community mental health care services. According to the studies reviewed, mental illness is a chronic burden that leads to stressful situations for both MHCUs and their families.

## **2.8 CONCLUSION**

In this chapter, various literature reviews on the lived experiences of young people living with MHCUs were reviewed and discussed with regard to mental health and mental illness, health systems and caring for the mentally ill, policy frameworks in the care of MHCUs at home, mental illness and the family, and community care of the mentally ill. It was discovered that research on the lived experiences of young people living with MHCUs is very limited, both internationally and in South Africa. Of the studies found, some were as old as 2004, 2006 and 2012. In Chapter 3, the research design and method will be discussed.

## **CHAPTER 3**

### **RESEARCH DESIGN AND METHOD**

#### **3.1 INTRODUCTION**

The research method is the steps, procedures and strategies for gathering and analysing data in a study (Polit & Beck 2012:733). Chapter 2 reviewed the literature on the lived experiences of young people living with MHCUs. The purpose of this chapter is to outline the research steps and procedures that were followed in order to answer the research question.

This chapter discusses the research design, qualitative research, and descriptive phenomenology. The research methodology, including population, sampling and data collection and analysis, are also presented.

#### **3.2 RESEARCH QUESTION**

A research question is a clear, concise interrogative statement that is worded in the present tense and it guides the implementation of the study (Grove et al 2015:147). Furthermore, it is a description of exactly what issues the research intends to acquire information about and is the foundation of the study (Moule & Goodman 2014:79; Parahoo 2014:150; LoBiondo-Wood & Haber 2014:26). The researcher sought to investigate the lived experiences of young people living with MHCUs in order to gain insight into their needs and how their daily coping can be maximised. The research questions are as follows:

- What are lived experiences of young people living with MHCUs?
- What are the coping strategies used by young people living with MHCUs?
- What are the needs of young people living with MHCUs?



### **3.3 PURPOSE AND OBJECTIVES**

After the research problem was discussed in Chapter 1, the study's purpose and objectives were presented as:

#### **3.3.1 Purpose**

The research purpose is a clear, concise statement of the specific goal or focus of a study (Grove et al 2015:131) and it assists researchers and readers to be clear about what is being researched (Parahoo 2014:150). In this study, the researcher sought to investigate the lived experiences of young people living with MHCUs in order to gain insight into their needs and how their daily coping can be maximised.

#### **3.3.2 Objectives**

The research objectives provide details of what the study is expected to achieve (Parahoo 2014:151). The research design and methodology selected in this study addressed the study objectives, which were:

- To explore and describe the lived experiences of young people living with MHCUs.
- To determine the coping strategies of young people living with MHCUs.
- To make recommendations for mechanisms to support young people living with MHCUs.

### **3.4 RESEARCH DESIGN**

Numerous authors define a research design as a plan that describes how, when, and where data are to be collected and analysed, and it also represents the thinking, beliefs, and strategies of the researcher (Parahoo 2014:164; LoBiondo-Wood & Haber 2014:57; Polit & Beck 2014:390).

In this study, a descriptive phenomenological design was used to assist the researcher to examine the lived experiences of young people living with MHCUs through the descriptions that they were providing (Brink et al 2012:121). By using the descriptive phenomenological design, the researcher was able to describe the lived experiences of the young people living with MHCUs and gain insight into what their lived experiences were and the meaning attached to those experiences. The goal of phenomenology is to describe lived experiences (Streubert & Carpenter 2011:74). According to Munhall (2012:129), phenomenology is the study of the individual's life-world as experienced, rather than as conceptualised, categorised, or theorised.

Phenomenologists state that experience should be examined in the way it occurs, as it is interested in understanding how individuals come to know their own experience of a phenomenon, which allows them to identify the essential qualities of that experience (Polit & Beck 2014:48; Mills & Birks 2014:183). The researcher investigated the lived experiences of young people living with MHCUs with the belief that critical truths about reality were grounded in their lived experiences (Polit & Beck 2014:270).

The researcher used a descriptive phenomenological design in order to describe ordinary conscious experiences of everyday life for young people living with MHCUs. Authors such as Polit and Beck (2014:270) state that phenomenologists view human existence as meaningful and interesting because of people's consciousness of that existence. In this study, the researcher conducted in-depth interviews in the homes of the participants. Purposive sampling was used as advocated by the phenomenological design since the researcher chose people who could answer the research questions (Parahoo 2014:274).

Phenomenological research advocates the use of four steps such as bracketing, intuiting, analysing, and describing in descriptive phenomenology in order to avoid bias and to enter the participants' home with an open mind (Brink et al 2012:122; Polit & Beck 2012:495). The researcher put aside what she knew about the lived experiences of the young people living with MHCUs and remained open to their experiences as described by the young people. The researcher also reviewed data again and again until there was a common understanding (Brink et al 2012:122).

Authors such as Parahoo (2014:214) advocates for the use of phenomenological reduction or *époché* to describe the process of bracketing or suspending previous knowledge of the experience in order for the researcher to reveal what they lived experiences of young people living with MHCUs really means and not what she expects it to mean. Phenomenologists believe that suspension of all pre-conceived ideas assists the researcher to reveal the true lived experience (Brink et al 2012:122; Parahoo 2014:214; Polit & Beck 2012:495; LoBiondo-Wood & Haber 2014:113).

According to Parahoo (2014:214), there were two processes that are crucial to reveal the essence of a phenomenon, which are bracketing and imaginative variation, which examine what people say about the phenomenon. In this study, the researcher used a reflexive journal in order to bracket any pre-conceived ideas (Mills & Birks 2014:183). The researcher jotted down all pre-conceived ideas about the experiences and put them aside. She then entered the participants' homes with an open mind. Polit and Beck (2014:390) explain reflexivity as the critical self-reflection about one's own biases, preferences, and preconceptions.

### **3.5 METHODOLOGY**

According to Brink et al (2012:199), a research methodology is to inform the reader of how the investigation will be carried out, in other words, what the researcher did to solve the research problem or to answer the research questions.

#### **3.5.1 Research approach**

In this study, a qualitative research approach was used as it assisted the researcher to explore the lived experiences of the young people living with MHCUs in totality through unstructured interviews in their homes. It also supported the researcher to gain insight into their needs and how their daily coping can be maximised (Creswell 2014:241; LoBiondo-Wood & Haber 2014:581; Polit & Beck 2012:489). Likewise, the researcher in this study was interested in the daily lived experiences of young people living with MHCUs, how these experiences have affected or shaped their lives, and their daily activities as young people.

According to Polit and Beck (2014:389), qualitative research is the investigation of phenomena, typically in an in-depth and holistic fashion, through the collection of rich narrative materials using a flexible research design. The researcher used a qualitative method in this study because it entails collecting data in a setting of everyday life and it explains the meaning of a phenomenon (Saks & Allsop 2013:27).

The qualitative research was applicable for this study as it resembles everyday conversations and observations, and it also relies on methods that allow researchers into the personal, intimate and private world of participants (Parahoo 2014:59). In this study, the researcher was the primary data collecting instrument.

#### **3.5.1.1 Characteristics of qualitative research**

The essential distinguishing characteristic of qualitative approaches is exploration as a means to understand the perceptions and actions of participants from their perspectives (Parahoo 2014:56). According to Polit and Beck (2014:393), qualitative research often involves using a multiple collection method called triangulation. In this study, the researcher observed, interviewed, and took field notes during data collection with the participants. An inductive approach is also a feature of qualitative approaches, wherein the researcher listens to and observes the participants without any interference during an interview (Parahoo 2014:57).

Interactive and reflexive processes are used in qualitative research whereby the researcher takes part in the study by being the primary data collection instrument and turns holistic, striving for understanding of the whole (Polit & Beck 2014:266; Streubert & Carpenter 2011:22). In this study, holism refers to participants' opportunity to talk about the totality of their lived experiences of living with MHCUs. In qualitative research, flexible methods are used, thus the methods resemble everyday conversations and observations.

Qualitative researchers are not bound by sample size; therefore, the researcher often collects data until there is no new information offered by the participants. That is, data is now repeating itself. According to Saks and Allsop (2013:27), in qualitative research knowledge is constructed by the participants, meaning that it seeks to understand the

subjective meanings of the participants. Data are also naturalistic, in that they are collected in the setting of everyday life, for example, in the homes of the participants. Qualitative research involves ongoing analysis of data to formulate subsequent strategies and to determine when data collection is complete (Polit & Beck 2012:487).

### **3.5.2 Population and sampling**

#### **3.5.2.1 Population**

Polit and Beck (2014:387) describe the population as the entire set of individuals or objects having some common characteristic. In this study, the population was young people living with MHCUs in Dikgale area, Limpopo province. The target population was all young people between ages of 18-24 years living with MHCUs in Dikgale area, Limpopo province.

#### **3.5.2.2 Sampling procedure**

According to Polit and Beck (2014:391), sampling is the process of selecting a portion of the population to represent the entire population. In this study, purposive sampling under the non-probability sampling method was used based on the researcher's judgement about who was knowledgeable about the lived experiences of young people living with MHCUs (Creswell 2014:246; Parahoo 2014:269). Non-probability sampling is the selection of sampling units from a population using non-random procedures (Polit & Beck 2014:386). Numerous authors in qualitative research advocate for the use of two principles guiding the selection of a sample in phenomenological studies. These are: all the participants have experienced the phenomenon under the study, and must be able to articulate what it is like to have lived that experience (Brink et al 2012:139; Polit & Beck 2014:287). Young people between the ages of 18-24 years living with MHCUs who could attest to the daily life situations of living with MHCUs, were selected.

#### **3.5.2.3 Inclusion criteria**

An inclusion criterion is the criteria that specify population characteristics (Polit & Beck 2012:274). In this study, the inclusion criteria were:

- Young people /adolescents between the ages of 18-24 years living with MHCUs at Dikgale area, Limpopo province.
- A willingness to participate.
- Living with MHCUs for 2 years and longer.

#### **3.5.2.4 Exclusion criteria**

- Adolescents below the age of 18 years.
- Those not living with MHCUs.
- Adolescents above the age of 24years.

#### **3.5.3 Sample size**

Polit and Beck (2014:286) state that the sample size in qualitative research is usually determined based on informational needs. In this study, the guiding principle was data saturation, meaning that the researcher continued sampling to the point where information was repeated and no new information was obtained. According to Munhall (2012:544), data saturation determines the sample size in qualitative research. The researcher used a projected sample size of not more than 10 participants with the final sample size determined by data saturation (Polit & Beck 2014:287; Moule & Goodman 2014:293).

#### **3.5.4 Data collection procedure**

Data collection is the gathering of information to address a research problem (Polit & Beck 2012:725). The following methods for collecting data are used in qualitative research: observation and interviews. Brink et al (2012:150) explain observation as the technique for collecting descriptive data on behaviour, events, and situations. The

observation method is used to increase researchers' understanding when used in combination with interviews (Parahoo 2014:334). Authors such as LoBiondo-Wood and Haber (2014:579), Brink et al (2012:157), and Creswell (2014:246), believe that interviewing is a method of data collection in which the researcher questions participants in a face-to-face encounter. According to Polit and Beck (2014:186), the response rate tends to be high in face-to-face interviews because participants are less likely to refuse to talk to the researcher. Interviews are also feasible and it can produce additional information through observation of the participants' behaviour. Interviews are useful when participants cannot be directly observed and it allows the researcher to take control over the line of questioning. It also gives the participants an opportunity to provide historical information (Creswell 2014:191).

In this study, unstructured interviews were used because it allowed the participants to talk freely about their lived experiences and assisted the researcher to explore and describe the lived experiences of young people living with MHCUs. Furthermore, the unstructured interviews also assisted the researcher to directly collect information from the participants as the primary data collection instrument. Unstructured interviews are also referred to as in-depth interviews wherein the researcher seeks to understand the experiences of others and the meaning they attribute to the experience (De Vos, Strydom, Fouché & Delport 2011:358).

Unstructured interviews produce more in-depth information on the participants' beliefs and attitudes than can be obtained through any other data-gathering procedure (Brink et al 2012:158). The researcher conducted unstructured interviews in the homes of the participants because the format was informal, non-directive, focused, narrative, and open (Parahoo 2014:313). The home situation offered a real-world and naturalistic setting which is advocated by phenomenologists for exploring participants' lived experiences (De Vos et al 2011:316; Polit & Beck 2012:489; Brink et al 2012:120).

The researcher ensured that the interview process was conducted according to the research protocol (Annexure B) which consists of two sections. Section A was related to the demographic data of the participants which enabled the researcher to describe the profile of the study participants, and section B consisted of three broad or central open-ended questions. Audio-recordings of the interviews were used with the

permission of the participants. Data were collected until data saturation was reached. Data saturation is a point when data collection can cease, and it occurs when the information being shared with the researcher becomes repetitive (LoBiondo-Wood & Haber 2014:577).

According to Creswell (2014:241), the central question in qualitative research is a broad question posed by the researcher that asks for an exploration of the central phenomenon or concept in a study. At the start of the interview process, the researcher introduced herself to the participants, using the language used by the participants to encourage openness. The participants were reassured and encouraged to feel free to answer the questions. Small talk was initiated with the participants to break the ice before actual questioning started. The purpose and objectives of the study were also stated, as well as the duration of the interview, which was 30-45 minutes. Confidentiality of the information was emphasised to the participants. Recorded interviews were labeled and participants' real names were not used. Signed voluntary consent was confirmed. The participants were informed that they could withdraw from the study at any time without any penalty.

During the interviews, the researcher conveyed non-verbal communication such as nodding her head and listening attentively without interrupting the participants. Three open-ended questions were asked: 'How will you describe your experience of living with aMHCUs?' 'What are coping strategies used by young people living with MHCUs?' and 'What are the needs of young people living with MHCUs?' The open-ended questions were used in order to allow the participants to use their own words (LoBiondo-Wood & Haber 2014:280). Probing was done guided by the responses of the participants.

The main points were summarised and discussed with the participants at the end of each interview. The researcher notified the participants about the time remaining for the interview and asked the participants if there was anything else that they would like to tell her or if they had any other questions. The researcher asked the participants if they would mind being contacted again.



Audio-recorded interviews were listened to and checked for audibility and for completeness immediately after the interview was over (Polit & Beck 2012:543). The audio-recorder and field notes were kept confidential in a safe place.

The researcher applied the following techniques during interviews: exploring, reflection, paraphrasing, minimal verbal response, clarification, and reflective summary.

#### **3.5.4.1 Piloting**

According to LoBiondo-Wood and Haber (2014:581), a pilot study is a small, simple study conducted as a prelude to a larger-scale study that is often called the “parent study”. The purpose of a pilot study was to investigate the feasibility of the proposed study and to detect possible flaws in the data collection instrument and methodology (Brink et al 2012:174). The pilot study assisted the researcher to develop her interviewing skills. In this study, the researcher conducted the pilot study in order to check if the questions that she was going to ask would yield the information that was required. The pilot study was tested on a small number of participants prior to the main study, to also determine the quality of the audio-recorder. Three participants were recruited face-to-face at the Health Care Centre on follow-up review days, which were every Thursday, and permission was asked from all MHCUs living with young people between ages of 18-24 years. The researcher selected those young people between the ages of 18-24 years living with MHCUs who could attest to the daily life situations of living with MHCUs.

Data was collected in the homes of the participants through face-to-face unstructured interviews which lasted 30-45 minutes. Three open-ended questions were asked. ‘How will you describe your experience of living with MHCUs?’, ‘What are coping strategies used by young people living with MHCUs?’ and ‘What are the needs of young people living with MHCUs?’ Probing questions were then asked according to the responses of the participants. The three participants who were used in the pilot study’s results were not included in main study.

### **3.5.4.2 Characteristics of data collection instrument**

Interviews are conversational and interactive. They are focused and discursive, use a broad question, sometimes called a grand tour question, use open-ended questions, probing and follow-up questions, and ask questions such as 'what'. Interviewing is a flexible technique allowing the researcher to explore in-depth issues, have high response rates, and allow the researcher to access personal information (De Vos et al 2011:348; Polit & Beck 2012:536; Moule & Goodman 2014:352).

### **3.5.4.3 Recruitment of the participants**

The researcher visited the Health Care Centre on psychiatric days which were every Thursday to recruit the participants. Purposive face-to-face recruitment was done on follow-up review days in this study because it is usually more effective than solicitation by a telephone call, letter, or email (Polit & Beck 2012:287). The researcher talked to the group of MHCUs about the study, and those who had children between 18-24 years were invited to approach the researcher. The point of entry to the participants' home was negotiated. The researcher requested contact details and made follow-up arrangements to meet the participants to sign the consent forms and conduct the interviews in their homes. All young people between the ages of 18-24 years living with MHCUs who could attest to the daily life situations of living with MHCUs were recruited.

### **3.5.4.4 Voice recording and transcription**

An audio-recorder was used to record the interviews in this study in order to take detailed information of what the participants said, to ensure that interview data were participants' actual verbatim responses (Polit & Beck 2012:534). Permission to use an audio-recorder was obtained from the participants. The audio-recorder assisted the researcher to concentrate on the interview and where to go next (De Vos et al 2011:359).

The audio-recorder was first piloted on a small population of the study before recording the sample population in order to check its quality and appropriateness. All data tapes were labeled with a code number and the data collection date. The names of the

participants were not used. A code number was used to refer to any of the records of participants' information that were retained within the study.

The researcher listened to the recorded interviews for audibility and completeness immediately after each interview and also gave the participants an opportunity to listen to the recorded interview after the session. The researcher kept recorded interviews in a safe and confidential place after the session.

#### **3.5.4.5 Field notes**

Numerous authors in qualitative research advocate for the use of field notes (De Vos et al 2011:359; Polit & Beck 2014:381; LoBiondo-Wood & Haber 2014:276). Field notes refer to data kept by researchers prior, during and after their interaction with their participants (Parahoo 2014:367). According to Polit and Beck (2012:548), field notes contain a narrative account of what is happening in the field and it must provide information about the time, place, and participants to portray the situation fully. The researcher interpreted these observations. The purpose of the field notes is to assist the researcher to synthesise and understand the data. Therefore, it is crucial to write full and accurate notes during the interviews.

Field notes are both descriptive and reflective and can be categorised according to their purpose, such as objective descriptions of the events, conversations, and the context in which it occurred. The researcher wrote notes on the lived experiences of the young people living with MHCUs as they occurred and recorded what she saw, heard, and observed during the interviews. The field notes assisted the researcher to remember and explore the process of the interview. Field notes were kept in a safe and confidential place.

#### **3.5.5 Data management and analysis**

Qualitative data analysis is the organisation and interpretation of narrative data for the purpose of discovering important underlying themes, categories, and patterns of relationships (Polit & Beck 2012:739). In this study, Colaizzi's approach was used to

analyse data (LoBiondo-Wood & Haber 2014:114; Polit & Beck 2012:566). Some of the steps used entail:

#### Step 1

The researcher listened to and transcribed the statements into words and read and re-read each description provided by young people living with MHCUs.

#### Step 2

The researcher extracted significant statements that were related to the lived experiences of young people living with MHCUs.

#### Step 3

The researcher formulated meanings for each significant statement being described by young people living with MHCUs.

#### Step 4

The researcher formulated meanings into clusters of themes.

#### Step 5

The researcher wrote an exhaustive description of the results and condensed them into a statement of the fundamental structure of lived experiences of young people living with MHCUs.

#### Step 6

The researcher continued to refer back to her field notes and audio-recorder in order to ensure faithfulness to the descriptions provided by young people living with MHCUs.

#### Step 7

The researcher asked some participants to listen to the audio-recordings immediately after the interview in the field, and both agreed that the audio-recorder captured their lived experiences.

### 3.6 MEASURE TO ENSURES TRUSTWORTHINESS

The researcher maintained scientific rigor through openness, relevance, epistemological and methodological congruence, and thoroughness in the data collection and data analysis process (Brink et al 2012:126; Polit & Beck 2012:745).

Table 3.1 shows the strategies used and how they were applied in the study.

**Table 3.1: Strategies, activities and application used**

STRATEGIES	ACTIVITIES	APPLICATION
Credibility	Prolonged engagement	<ul style="list-style-type: none"><li>• The researcher ensured that the findings reflect participants' lived experiences.</li><li>• The researcher spent time with the participants establishing rapport and building trust before and during interviews.</li><li>• The researcher stayed with the participants until data saturation was reached.</li><li>• The researcher ensured the credibility of the study by capturing a holistic understanding of the phenomenon under study.</li><li>• The researcher recorded in-depth interviews with intermittent probes for clarification using an audio-recorder.</li><li>• Data weretranscribed and taken back to the participants for them to check if it is a true reflection of their viewpoints (Brink et al 2012:172).</li><li>• This was done during data collection in the field where the researcher gave some of the participants the audio-recorder to listen to it immediately after the interviews, and a summary was done after each interview</li></ul>

STRATEGIES	ACTIVITIES	APPLICATION
		during data collection in order to verify data with the participants.
	Member checking	<ul style="list-style-type: none"> <li>• Ongoing member checking was done through probing during data collection (Polit &amp; Beck 2014:328).</li> </ul>
Dependability	Stepwise replication	<ul style="list-style-type: none"> <li>• All aspects of this study, such as methodology, characteristics of the sample, data collection procedures, data analysis and quality check, were fully described.</li> <li>• The study ensured if it was to be repeated in a similar context, similar results could be attained by other researchers (Brink et al 2012:172).</li> </ul>
Confirmability	Triangulation Reflexivity	<ul style="list-style-type: none"> <li>• In this study, the researcher ensured that the findings reflected the participants' voices and conditions of inquiry; not the researcher's biases.</li> <li>• The interpretations of data were not influenced by the researcher.</li> <li>• Reporting of findings was supported with verbatim quotes from the participants' responses (Brink et al 2012:173).</li> <li>• The researcher submitted transcripts to her supervisor who assisted in identifying themes and sub-themes. The results were compared and similarities were established.</li> <li>• The researcher observed, wrote field notes and interviewed the participants during data</li> </ul>

STRATEGIES	ACTIVITIES	APPLICATION
		<p>collection to ensure data accuracy (Polit &amp; Beck 2014:393; Munhall 2012:521).</p> <ul style="list-style-type: none"> <li>• The researcher used a reflexive journal in order to bracket any pre-conceived ideas (Mills &amp; Birks 2014:183).</li> <li>• The researcher wrote down all pre-conceived ideas about the experiences, put them aside, and entered the participants' homes with an open mind (Moule &amp; Goodman 2014:407).</li> <li>• Numerous authors such as Polit and Beck (2014:390), Munhall (2012:321), and Streubert and Carpenter (2011:34), believe that reflexivity is the critical self- reflection about one's own biases, preferences, and preconceptions.</li> </ul>
Transferability	Thick descriptions	<ul style="list-style-type: none"> <li>• The researcher gave a rich, thorough, and vivid description of the research context, the people who participated in the study, and the experiences and processes observed during the inquiry (Polit &amp; Beck 2014:331).</li> <li>• The researcher described the findings in-depth in order to produce thick descriptions of the lived experiences of young people living with MHCUs.</li> <li>• The researcher compared the findings of the study with what other researchers had established in their literature.</li> <li>• Thick descriptions entail the collection and provision of sufficiently detailed</li> </ul>

STRATEGIES	ACTIVITIES	APPLICATION
		descriptions of data within the given context, and reporting on them (Brink et al 2012:173).
	Purposive sampling	<ul style="list-style-type: none"> <li>• Prospective participants were purposively recruited and selected by the researcher in terms of their knowledge of the phenomenon under investigation and their locations (Brink et al 2012:173).</li> <li>• Purposive sampling has the logic and power of selecting information-rich cases for the study (Streubert &amp; Carpenter 2011:90).</li> <li>• Young people between ages of 18-24 years living with MHCUs who could attest to the daily life situations of living with MHCUs were selected to participate in this study.</li> </ul>
	Data saturation	<ul style="list-style-type: none"> <li>• The researcher collected data from the participants until data saturation was reached.</li> <li>• Data saturation occurs when additional participants provide no new information and when the themes that emerge become repetitive (Brink et al 2012:173).</li> </ul>
Authenticity		<ul style="list-style-type: none"> <li>• The report of the researcher conveyed the feeling and tone of the participants.</li> <li>• The report invites readers into the vicarious experience of the lives of young people living with MHCUs as described, and enables readers to develop a heightened</li> </ul>



STRATEGIES	ACTIVITIES	APPLICATION
		sensitivity to the issue being depicted (Polit & Beck 2014:323).

### **3.7 ETHICAL CONSIDERATION**

Ethics is a system of moral values that is concerned with the degree to which research procedures adhere to professional, legal, and social obligations to the study participants (Polit & Beck 2012:727).

#### **3.7.1 Ethical issues related to sampling**

In this study, voluntary participation was encouraged. The participant had a choice of whether or not to give consent. Young people living with MHCUs were requested to voluntarily be part of the study and indicated that by a signed written consent. The researcher informed participants about the purpose of the study, the research methodology, the benefits of the study, and the right to refuse and withdraw from the study without penalty before being requested to participate voluntarily. Participants also received information on the informed consent, including the type of information, the degree of understanding, and the fact that the participant had a choice of whether or not to give consent (Brink et al 2012:38).

As part of the ethical consideration to ensure no harm occurs to participants, the interaction with participants (data collection) was postponed until ethical approval from the institutions of study was sought. The Research Ethics Committee of the Department of Health Studies at UNISA also assessed and ascertained through the informed consent and detailed research design that no potential risk would be incurred by participants.

Dealing with young people as a vulnerable group on the sensitive issue of living with MHCUs, could evoke psychological discomfort to the participants. In the event that participants experienced emotional distress during the interviews, and should they need counselling, the researcher arranged for a support system (counselling) with one

of the trained psychiatric nurses at the local clinic to be used for referral of the participants. Prospective participants were purposefully recruited for the purpose of sharing knowledge.

According to Brink et al (2012:141), purposive sampling is based on the judgement of the researcher to select those participants or objects that are typical or representative of the study phenomenon, or who are especially knowledgeable about the question at hand. The researcher selected those young people between the ages of 18-24 years living with MHCUs who could attest to the daily life situations of living with MHCUs.

### **3.7.2 Ethical considerations related to data collection**

Any records from the study were kept confidential to the extent possible by law. The records were reviewed by people responsible for making sure that the study was done correctly, including members of the research ethics committee at UNISA. A code number was used to refer to any of the records of participants' information that was retained within the study. When the study findings are published, care will be taken that reporting donot specifically identify participants' involvement in the study in any manner.

An audio-recorder was used to record the interviews in this study in order to take detailed information of what the participants were saying and to ensure that interview data were participants' actual verbatim responses (Polit & Beck 2012:534). The researcher used open-ended questions, an audio-recorder, and verbatim transcriptions to increase data accuracy. Field notes, together with the verbally transcribed information, assisted the researcher to achieve the most comprehensive and accurate description of the phenomenon (Streubert & Carpenter 2011:91). Permission to use the audio-recorder was obtained from the participants. The researcher kept recorded interviews in a safe and confidential place after the session.

### **3.7.3 Ethical principle**

The following ethical principles were used to ensure freedom of participation, and prevention of harm. Maintaining participants' privacy through anonymity and confidentiality were central to the positioning of the study.

#### **3.7.3.1 Ethical permission**

Permission to conduct the study was granted by the Research Ethics Committee of UNISA. Approval was also granted from the Department of Health Limpopo Research Committee and the Department of District Office Primary Health Care to enter the Health Care Centre for recruitment. Permission to conduct the study was received from the operational manager of the local Health Care Centre. Permission to conduct the study was also granted from Dikgale Tribal Authority in order to be able to enter the participants' homes (Annexure I).

#### **3.7.3.2 Principle of respect for persons**

This principle explains that individuals have the right to self-determination, and individuals with diminished autonomy, such as children, people with mental disorders, unconscious patients and institutionalised patients, require additional protection (Brink et al 2012:35). The researcher informed the participants that they have the right to decide whether or not to participate in the study, without the risk of penalty or prejudicial treatment. Participants were informed that they could withdraw from the study at any time, and they have the right to refuse to give information and to ask for clarity about the purpose of the study. The researcher respected the rights, religion and tradition of the participants, and encouraged voluntary participation. The researcher did not select the participants according to their vulnerability (Brink et al 2012:35).

According to Brink et al (2012:38), the ethical principle of voluntary participation and protecting the participants from harm are formalised in the concept of informed consent. Informed consent comprises of three major elements that include the type of information, the degree of understanding, and the fact that the participant has a choice whether or not to give consent (Brink et al 2012:38). In this study, young people living with MHCUs were requested to voluntarily be part of the study and indicated their willingness by signing written consent to participate.

### **3.7.3.3 Principles of beneficence**

Beneficence is a fundamental ethical principle that seeks to maximise benefits for the study participants and prevent harm (Polit & Beck 2012:720). The researcher ensured that participants were protected from physical, psychological, emotional, spiritual, economic, or legal harm. Even after careful consideration on the part of the researcher, there remained the possibility that interaction with the participants might unintentionally evoke harm. In the event that participants experienced emotional distress during interviews, and should they have needed counselling, the researcher arranged a support system (counselling) with one of the trained psychiatric nurses at the local clinic to be used for referral of the participants. Any records from the study would be kept confidential to the extent possible by law. The audio-recorder and field notes for recorded interviews would be kept in a safe and confidential place. The records were reviewed by people responsible for making sure that the study was done correctly, including members of the research ethics committee at UNISA. A code number was used to refer to any of the records of participants' information that were retained within the study. When the study findings are published, care would be taken that reporting do not specifically identify participants' involvement in the study.

### **3.7.3.4 Principles of justice**

According to Brink et al (2012:36), justice refers to the participants' right to fair selection and treatment. The researcher ensured that the participants were selected with fairness; only young people between the ages of 18-24 years who were living with MHCUs were used in the study. The researcher respected the appointments for interviews, the cultural value and privacy of the participants, and always arrived at the agreed upon time. The researcher requested permission from the participants to audio-record the interviews. Information collected from the participants remained confidential and no names were used.

### **3.7.3.5 Informed consent**

Authors such as Streubert and Carpenter (2011:61) and Polit and Beck (2014:87) explain that informed consent means that participants have adequate information about the study, comprehend the information, and have the power of free choice, enabling them to voluntarily consent to or decline participation.

In this study, the researcher explained the advantages and benefits of the study to the participants. She informed the participants that their participation is voluntary and they have the right to refuse or to withdraw from the study at any time without punishment. The researcher also explained the objective of the study, the methods of collecting data, and the duration (interviews, audio-recording device, and field notes) to the participants. Information about the nature of commitment, participants' selection, alternatives, compensation, a confidentiality pledge, and contact information were given to the participants before they signed the consent form (Polit & Beck 2012:158). The participants received information about a support system (counselling) that was arranged for them should they require counselling after the interview. The researcher's identification and affiliation, as well as consent forms, were given to the participants. Participants showed their willingness to participate by attaching their signatures on the consent form as proof of not being coerced to participate (Annexure A).

### **3.8 CONCLUSION**

In this chapter, the research design and method, the population, sampling procedure, and ethical issues related to sampling were discussed. The data management and analysis, measures to ensure trustworthiness, and ethical considerations were also described. In Chapter 4, the analysis, presentation and description of the research findings will be discussed.

## **CHAPTER 4**

### **ANALYSIS, PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS**

#### **4.1 INTRODUCTION**

This chapter presents the analysis and description of the study findings. The qualitative inquiry intended to explore and describe the lived experiences of young people living with MHCUs. Themes and sub-themes that emerged from data will be presented in detail. Answers to the following research questions were sought through this inquiry:

- What are the lived experiences of young people living with MHCUs?
- What are the coping strategies used by young people living with MHCUSs?
- What are the needs of young people living with MCHUs?

#### **4.2 DATA MANAGEMENT AND ANALYSIS**

The analysis of qualitative data from in-depth, audio-recorded, unstructured interviews was done following the steps of Colaizzi's (1978 in Polit & Beck 2012:566) analysis process as detailed in the previous chapter (Refer to Section 3.5.5). This entailed a systematic process together with continuous reflection about the data. Following extensive reading and re-reading of the transcribed audio-recordings of the participants' responses, several themes and sub-themes emerged from the data. These are presented in a table format indicating the themes and sub-themes which will precede the discussion of each theme's categories. The discussion will be supported by excerpts from the verbatim interview quotes of participants.

##### **4.2.1 Demographic profile of study participants**

A total number of 10 participants who were living with MHCUs at the time of the research were engaged in unstructured interviews and their ages ranged between 19-

23 years. Table 4.1 indicates the biographical profile of the participants. The biographical data has been used to focus and contextualise the study findings.

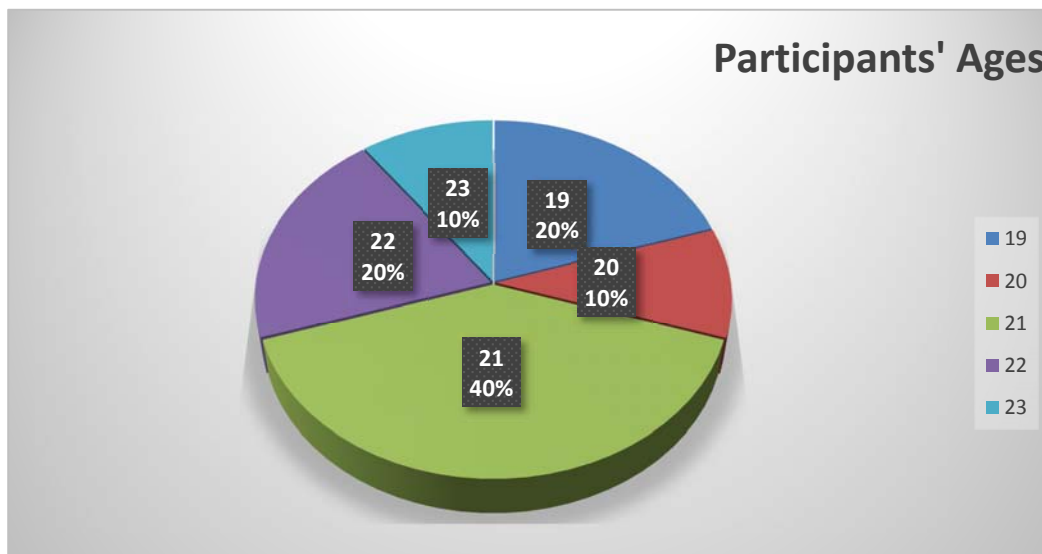
**Table 4.1: Characteristic profile of study participants**

CHARACTERISTIC	NUMBER OF PARTICIPANTS
<b>Ages:</b>	
- 19	2
- 20	1
- 21	4
- 22	2
- 23	1
<b>Gender:</b>	
- Female	5
- Male	5
<b>Level of schooling:</b>	
- High school	6
- Tertiary level	2
- Drop out	2
<b>MHCU in family:</b>	
- Parents	7
- Sibling	1
- Uncle	2
<b>No of years living with MHCU:</b>	
- 0-5yrs	1
- 6-12yrs	2
- <12yrs	7
<b>Total number of participants</b>	<b>10</b>

#### **4.2.1.1 Gender and age of the participants**

An equal number of male (n=5) and female (n=5) participants were interviewed. Though the study proposed age distribution of participants between 18-24 years, only

young people aged 19-23 years formed the study sample. The majority of participants (40%) were 21 years of age, as shown in Figure 4.1.



**Figure 4.1: Ages of study participants**

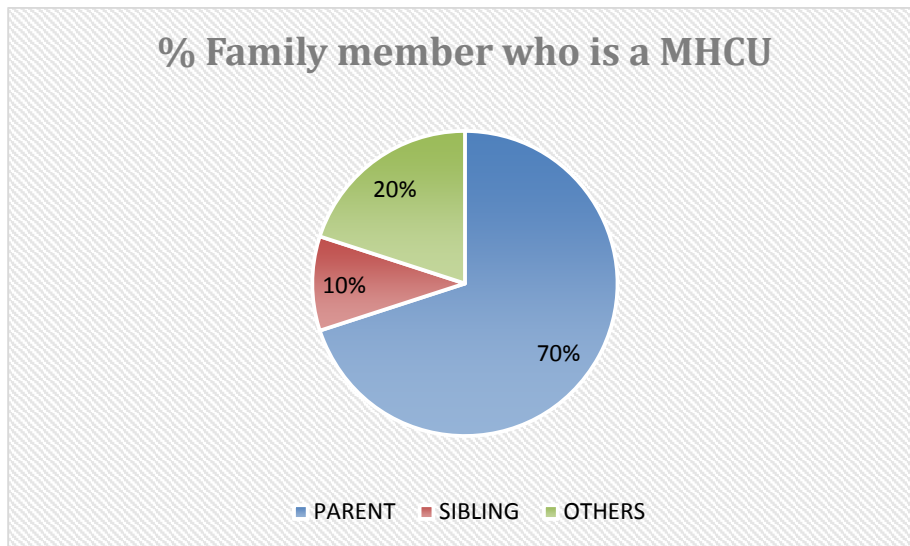
#### **4.2.1.2 Level of schooling**

The majority of participants were still studying at high school and at tertiary level (n=8). Some dropped out of school in Grade 9.

#### **4.2.1.3 MHCU in the family**

Most of the participants (70%) had biological parents diagnosed as MHCUs since their births, and thus were believed to be capable of making valuable accounts of what it is like to live with a MHCU. Of the biological parents as MHCUs, most were mothers (Refer to Figure 4.2). The longest period of living with the MHCU was experienced by those born to a MHCU parent, with the shortest period being 5 years.





**Figure 4.2: Family members who are MHCUs**

### 4.3 STUDY FINDINGS

Young people's descriptions of their lived experiences of living with MHCUs were analysed and categorised into 5 themes and 12 sub-themes as shown in Table 4.2. Themes are clusters of words with different meanings or connotations and are used to describe a structural meaning unit of data that is essential in presenting the results (Parahoo 2014:370; Polit & Beck 2014:393).

**Table 4.2: Themes and sub-themes**

THEMES	SUB-THEMES
<b>1: Psychological effects</b>	a) Ashamed and embarrassed b) Feeling of despair c) Fear and guilt
<b>2: Risk involved</b>	a) Danger to MHCUs b) Danger to the Family c) Danger to community
<b>3. Added responsibility</b>	a) Burden of care b) Non-adherence to treatment

THEMES	SUB-THEMES
<b>4: Effects on schooling performance</b>	a) Poor academic performance and progress b) Resulted drop-outs
<b>5:Coping strategies and support needed</b>	a) Individual coping mechanism <ul style="list-style-type: none"> <li>- Being accommodative</li> <li>- Avoidance and ignore</li> <li>- Smoking and alcohol abuse</li> </ul> a) Support system <ul style="list-style-type: none"> <li>- Family</li> <li>- Community</li> <li>- Economic</li> </ul>

#### 4.3.1 Study themes

##### 4.3.1.1 Theme 1: Psychological effects

Behavioural manifestations of mental illness displayed by MHCUs during times of relapse had severe psychological effects on the young people. The emotional strain and stress that prevail in their home environment was shown through various emotions.

**Table 4.3: Theme 1: Psychological effects**

Theme1: Psychological effects	Sub-themes
	a) Ashamed and embarrassed b) Feeling of despair c) Fear and guilt

### **a) Ashamed and embarrassed**

Most participants verbalised feeling ashamed and embarrassed by some untoward or inappropriate behaviours displayed by their MCHU relatives in public during relapses. Some of these behaviours include picking up papers, undressing in public, using abusive language, and calling other people witches. These excerpts emphasise this:

*“I was ashamed and afraid of going out because my father was shouting and talking things that do not make sense in the street and people were watching.”*

*“One day I was from the school, he was sent to the clinic, on the way to the clinic, he ran away and undress himself on the street while running; I felt bad because he is my uncle and people are laughing at him.”*

### **b) Feeling of despair**

Participants expressed that the situation of living with a MCHU devoid of parental love and the necessary support, make their lives hopeless. The pain and despondency from those still schooling is reflected in these responses:

*“It hurts me to realise that my mother is mentally ill.”*

*“We are running short of lot of things and motherly love here at home.”*

*“If I can fail this year, I am dropping out from school because nobody is taking care about me, and I am struggling to get things for the school.”*

### c) Fear and guilt

Participants expressed feelings of fear, anxiety and guilt due to the unpredictable actions and destructive behaviours of the MHCUs. Destructive actions within their homes or in the neighbourhood made some feel guilty and they blamed themselves. These are the responses of participants revealing their experiences of fear and guilt:

*“When my father broke windows in our neighbour’s house, I had to go and apologise.”*

*“When my mother start throwing stones on people I feared that she’d be hurt or hurt a person.”*

#### 4.3.1.2 Theme 2: Risk involved

Participants highlighted experiencing fear of the risks that their MHCU relatives’ lives and theirs are exposed to in the community. These include being humiliated and stigmatised in the community, attacks levelled on the MHCUs, and the young people being physically abused by their mentally ill family member. Witnessing destructive and embarrassing inappropriate behaviours from their parents or relatives made these experiences worse.

**Table 4.4: Theme 2: Risk involved**

Theme 2: Risk involved	Sub-themes
	a) Danger to MHCUs
	b) Danger to the Family/Participant
	c) Danger to community

##### a) Danger to MHCUs

Young people reported that witnessing behaviours during relapses within the family and in the community posed a risk of danger to the MHCU. The fear that people in the community may retaliate against the MHCUs when behaving inappropriately or

displaying aggressive behaviours was experienced by most participants. These responses affirm what participants witnessed:

*“When my father broke our neighbours’ windows insulting them of witchcraft, I feared that they would fight back and I had to go and ask for forgiveness on his behalf.”*

*“He started by throwing other people with stones on the street and doing some strange things.”*

*“My mother was standing in-front of the moving cars and getting inside of the bus without knowing where she is going.”*

*“I felt bad when my uncle is ill people laughing at him and disrespecting him.”*

#### **b) Danger to the family/participant**

Most participants’ responses showed how their environment is always full of unbearable violence and aggression. They revealed that as children, the lack of maternal love and living in constant fear caused tension and an unpleasant home environment. In some instances, they are forced to run for safety. These were the response from some participants:

*“Sometimes he breaks things at home such as beating walls, doors, moving fridge saying people are strangling him.’ I decide not to answer or argue with him for fear that he could attack me.”*

*“When my mother is sick I lock myself in the room because she says I am disrespecting her and I am also calling the police.”*

*“When my mother is ill the family becomes disrupted; sometimes my mother wants to beat me.”*

*“My uncle always beat my younger brother who is 18 years.”*

### **c) Danger to community**

The violent and destructive behaviours towards neighbours and property make the MHCU a danger to society. The following were the incidents experienced by most participants:

*“My uncle started by throwing other people with stones on the street and doing some strange things.”*

*“My father destroyed other peoples’ properties. ‘When I was there to fix the broken window, the woman of that house was very angry at me and talked bad things.”*

#### **4.3.1.3 Theme 3: Added responsibility**

Most participants highlighted that caring for MHCUs is an added load in their responsibilities. Thus, Uys and Middleton (2014:89) assert that continuous long-term care giving leads to significant stress that is often referred to as the family burden or the care giving burden.

**Table 4.5: Theme 3: Added responsibility**

<b>Theme 3: Added responsibility</b>	<b>Sub-themes</b>
	<b>a) Burden of care</b>
	<b>b) Non-adherence to treatment</b>

#### **a) Burden of care**

The care giving activities highlighted involved doing household chores, supervising the MHCU's movements 24hours a day, and ensuring the MHCU's compliance with medication. These deprived them of time to socialise and hang out with friends and

classmates, and some had to quit their jobs. Their schoolwork also suffered. Some of the participants' responses indicated this experience as follows:

*"I had to do all housework, such as cleaning, cooking and washing and I become exhausted and sleep. My mother is always demanding everything from me."*

*"My brother is wandering around; we have to always be guarding his movements."*

*"I have left my job in order to take care of him."*

*"I am the one who is taking care of my uncle, my siblings and my grandmother because she is partially blind. I cook, clean and wash for my uncle."*

#### **b) Non-adherence to treatment**

Young people reported being fully involved in ensuring that their family MHCUs are complying with treatment. This entails daily supervision of medication use, accompaniment to the clinic for review, and taking the MHCU to the hospital in times of relapse.

*"We used to see my uncles' tablets in the toilet. He takes the treatment by himself and no one is accompanying him to the clinic. Then I decided to be involved."*

*"We accompany him to the clinic and supervised him to take treatment. Sometimes he becomes sick walk through the night and we have to go out and look for him."*

#### 4.3.1.4 Theme 4: Effects on schooling performance

As most of the participants were still in school, they all attested to how their daily living experiences affected their school progress. Burns and Roos (2016:496) affirm that poor school performance should be viewed as a symptom that reflects an underlying difficulty that must be identified and managed. In the instance of this study, this was aggravated by the added responsibility of living with MHCUs as described in the previous sub-themes.

**Table 4.6: Theme 4: Effects on schooling performance**

<b>Theme 4: Effects on schooling performance</b>	<b>Sub-themes</b>
	<b>a) Poor academic performance and progress</b>
	<b>b) Resultant drop-outs</b>

##### **a) Poor academic performance and progress**

Most of the participants were old for their grades and reported several repeats of grades. Periodically missing class and under-preparedness for classwork were among highlighted reasons. The following participants said:

*“I failed three times at school; when in grade 10 my mother became ill and she was shouting and making a lot of noise and I was writing final examination. I also repeated grade 11 and grade 12.”*

*“My mother’s illness affected my studies, I had no time to study and I am even considering dropping out from school. This also affected my brothers, who also had repeated the grades.”*

*“Sometimes there are some arguments at home and this cause me to have difficulty in coping at school. I cannot concentrate in class and sleep in class.”*



## b) Resultant drop-outs

Some participants attested to the lack of support in the care of MHCUs that prompted them to leave school. The repeated failing and getting old in the grades made them feel embarrassed among peers and they faced being mocked by them.

*“I failed three times at school, grade 6, 7 and 10, I then decided to drop-out from the school because I was hurt by unkind remarks from other people.”*

*“Remarks that I am also affected by the illness and that’s why I fail.”*

The emotional strain and not coping led to some indulging in alcohol and substance abuse, leading to them dropping out from school. One participant revealed:

*“I started drinking alcohol to cope with what was happening at home and ended up leaving school.”*

### 4.3.1.5 Theme 5: Coping strategies and support needed

Coping refers to the process of striving to master environmental stressors or challenges (Uys & Middleton 2014:196). With the availability of healthy coping mechanisms and support systems, these situations could be successfully handled. Study participants, in the midst of their emotional strain and stress, highlighted the coping strategies they used in their daily living with MHCUs.

**Table 4.7: Theme 5: Coping strategies and support needed**

Theme 5: Coping strategies and support needed	Sub-themes
	a) Individual coping mechanism
	- <i>Being accommodative</i>
	- <i>Avoid and ignore</i>
	- <i>Smoking, alcohol and substance abuse</i>

#### **b) Support system**

- **Family**
- **Professional nurses**
- **Economic**

#### **a) Individual coping mechanisms**

##### **- *Being accommodative***

Participants felt forced to be accommodative and tolerant to all the strange behaviours of the MHCUs in order to avoid exacerbating the behavioural problems. Some had to comply to maintain a peaceful home environment or avoid being hurt. These are the responses that reflect the participants being accommodative:

*“I am patient with my father when he is talking alone because if I became impatient with him, he makes a lot of noise; I am patient, not answering him and keeping quite when he is angry.”*

*“I pretend as if I am coping but deep down I am feeling pain.”*

##### **- *Avoid and ignore***

Responses revealed that some participants resort to avoidance and isolation to escape from realities of their daily living experiences with MHCUs. The fear, anxiety, and embarrassment they find themselves experiencing due to aggressive and violent behaviours of the MHCUs, become partially relieved by just ignoring what is really happening. These excerpts confirm this:

*“I am ignoring him when he is doing strange things, it’s like switching off the fire by petrol.”*

*“I decide not to answer or argue with my father for fear that he could attack me.”*

*“When my mother is sick I lock myself in the room.”*

Some participants reported using church rituals such as ditaelo (rituals), playing gospel music, or attending church services to give themselves a break.

- **Smoking, alcohol and substance abuse**

Participants verbalised engaging in a number of risky behaviours such as smoking dagga and drinking alcohol in order to relieve the stress of living with MHCU. These excerpts reveal:

*“My mother’s illness affected me psychologically when I am growing up. I started smoking in order to relieve stress.”*

*“I thought if I go out with my friend and have alcohol drink, will come back and tolerate the situation at home and I ended up drinking a lot.”*

## **b) Support system**

- **Family**

Responses revealed that some participants are faced with caring for the MHCU alone, without assistance. This excerpt confirms this:

*“No one is giving us support. My other uncle who was giving us support has passed away.”*

Some participants voiced a feeling of support in the care of MHCU. The support system includes the other parent in the family where there are two parents, grand-parents, and elder siblings. These responses affirm what participants said:

*“My mother, my grandmother and my other brothers are helping in taking care of my father.”*

*“I am better because I have my brothers, my sister and my father who are giving me support.”*

- **Professional nurses**

Participants' responses revealed a lack of community involvement when living with MHCUs. Instead, they were faced with labeling, stigmatising and abuse from the community members. Participants voiced feeling hurt and frustrated because nurse professionals at the local clinic were not offering them support. These excerpts assert to this:

*"Neighbours were just watching and laughing without helping us."*

*"Community is distancing itself from us."*

*"I need a nurse to give us information on how to take care of my mother and guide us on how to relieve stress."*

- **Economic**

Participant responses showed how they were living in impoverished conditions and sometimes faced hunger as they are financially dependent on MHCUs' social grants. These responses confirm what the participants said:

*"We are running short of a lot of things here at home, such as food, clothes and school uniform."*

*"We are depending on my mother's social grant. My brother is doing some piece jobs."*

#### **4.4 CONCLUSION**

In this chapter, the data analysis, presentation, and description of the study findings for the lived experiences of young people living with MHCUs took place. Emerged themes and sub-themes were discussed. In Chapter 5, the study findings, with literature control, limitations, recommendations and conclusion, will be discussed.

## **CHAPTER 5**

### **DISCUSSION OF STUDY FINDINGS, WITH LITERATURE CONTROL, LIMITATION, RECOMMENDATIONS AND CONCLUSION**

#### **5.1 INTRODUCTION**

The previous chapter presented the data analysis and interpreted the findings. This chapter will further explore and synthesise the major findings of the study with supporting literature related to the study topic. According to De Vos et al (2011:134), a thorough literature review is the foundation for substantial useful research. Therefore, the findings have been correlated with the reviewed literature.

#### **5.2 RESEARCH DESIGN AND METHOD**

A qualitative research inquiry using a descriptive phenomenological design was undertaken to gain insight into the lived experiences of young people in their daily living with MHCUs in their families. Answers to the following questions were sought:

- What are lived experiences of young people living with MHCUs?
- What are the coping strategies used by young people living with MHCUs?
- What are the needs of young people living with MHCUs?

The objectives of this study were:

- To explore and describe the lived experiences of young people living with MHCUs.
- To determine the coping strategies of young people living with MHCUs.
- To make recommendations for mechanisms to support young people living with MHCUs.

### **5.3 THE MAJOR FINDINGS OF THE STUDY**

From the study themes and sub-themes discussed in the previous chapter, the following have been identified as the overarching findings that best describe the daily life experiences of young people living with MHCUs. These are:

- Young people living with MHCUs experience psychological effects.
- Young people living with MHCUs are faced with demands and responsibilities.
- Young people living with MHCUs experience adverse effects on their schooling performance.
- Young people living with MHCUs experience coping and support system needs.

#### **5.3.1 Psychological effects**

The findings of this study revealed that the participants' daily experiences of living with MHCUs are fraught with various challenges, hence, this becomes a source of emotional strain and stress. Generally, the illness of a family member, irrespective of the type and cause, has both reactions and consequence on the family as a whole. A study on the experiences of family members during the critical illness of a loved one admitted to an intensive care unit, revealed emotional turmoil among the family members (De Beer & Brysiewicz 2017:61).

With mental illness, the impact on both the physical and the mental health of the family members is well documented in numerous literature (Chang et al 2016:7; Abram & Stein 2013:609; Katz, Medoff, Fang & Dixon 2015:796; Muralidharan et al 2016:485; Marimbe, Cowan, Kajawu, Muchirahondo & Lund 2016:1; Nxumalo & Mchunu 2017:205). Continual family care brought about by the shift towards community care and deinstitutionalisation of people with mental illness, has seen many family caregivers immersed in emotional strain and stress (Jeyagurunath, Sagayadevan, Abdin, Zhang, Chang, Shafie, Rahman, Alingakar, Chong & Subramaniam 2017:1; Marimbe et al 2016:1).

Winther-Lindquist (2014:95) refers to emotional strain as the psychological, physical, and social pressures felt by a family when living with MHCUs, which affect diverse areas of a person's quality of life, ranging from physical pain to an inability to sustain social connections. Young people in this study revealed experiencing negative emotions such as feeling ashamed and embarrassed, as well as feeling despair, fear and guilt in their daily living with MHCUs as a manifestation of psychological distress. These vastly affected their social-emotional well-being. Several authors (Van Loon et al 2014:12; Trondsen 2012:182; Wittenberg, Saada & Prosser 2014:10; Chang et al 2016:1) concur with the finding of the study that children with a mentally ill parent may more frequently experience negative emotions, including anger, fear, and sadness. The unpredictable nature of the illness and behaviours of the MHCUs generate these negative emotions. According to Van Loon et al (2014:12), these negative emotions would heighten the risk of internalising problems such as depression and anxiety, and externalising problems such as aggressive and conduct behaviour in young people. These were alluded to by some of the study participants as experiences of outbursts of anger and emotional breakdowns such as crying for no apparent reason due to the situation at home. Mfidi (2016:121) also asserts that the heightened emotional arousal may compromise rational decision-making and make young people vulnerable to a range of internalising and externalising problems.

Studies on adult family caregivers' experiences also affirm these findings as a reflection of chronic stress and daily hassles due to the profound burden of care (Wittenberg et al 2014:10; Chang et al 2016:1; De Beer & Brysiewicz 2017:66; Shamsaei et al 2015:4).

Adolescence is viewed as a period full of developmental challenges for young people, which include the psychological development of autonomy, establishing intimate relationships, developing a sense of identity, sexuality, and educational and occupational achievement. Under normal circumstances, positive mastery of these challenges is attainable. However, with the psychological turmoil in their daily living with MHCUs, individual capacity to deal with these adversities may be jeopardised, leading to mental distress (Hutchinson, Roberts, Skurrlé & Daly 2016:619; Van Loon et al 2014:1202).

### **5.3.2 Demands and responsibilities**

The study findings revealed the added demands and responsibilities young people face in the care of MHCUs. Marimbe et al (2016:4), in their study on the perceived burden of care, reported coping strategies and a need for family care givers, as well as affirming the enormous burden that poses a significant impact on the family's quality of life. The chronic nature of mental illness and the dependency of MHCUs on caregivers signify the continuous long-term care giving. This is what was revealed in this study with participants having to assist the MHCUs with their daily activities, treatment compliance and supervision, accompaniment to reviews, and even 24-hour supervision of their movements.

According to Sanders et al (2014:257), living with the MHCU impacts on the psychosocial dynamics and adaptation among the entire family. The findings of this study affirm that young people experienced unmet expectations from their parents, role reversal and confusion; the parent's illness depriving them of parental love and care, and instead parents have to be cared for by them. Participants revealed the unbearable nature of the tremendous caring demand that is exhaustive in nature and denies them time to socialise with their peers. Socialisation influences how adolescents learn to express and regulate their affect, and impacts on psychological adjustment. The peers provide emotional support for adolescents and have the power to shape their emotional developments (Miller-Slough & Dunsmore 2016:287). Bjorgvinsdottir and Halldorsdottir (2014:41) affirm that a lack of time to interact with peers lead to social exclusion and thus aggravate emotional strain and stress.

The family dynamics, coupled with conflicts among each other and/or with the MHCUs that the participants highlighted in this study, especially during relapse periods, proved to increase the level of burden. Some participants were left to fend for themselves as sole providers of care with no family assistance. McCann, Bamberg and McCann (2015:207) state that shared responsibility among family members lessens the emotional burden of caring and provide the carer with time for relief, suggesting that this could be made possible through collective or multiple care giving and/or respite care. Multiple caregiving entails family members relieving each other during weekends or alternating in performing daily activities, whilst respite care involves making use of



alternate community resources like day-care centres or day hospitalisation. The latter is mostly seen in affluent Western countries, which is limited, if not absent, in most South African provinces.

The unpredictable living experiences with MHCUs, where proper planning for the daily work schedule is sometimes impossible, aggravate the burden of care. Participants in this study revealed that at one point, the living situation was stable and at the other, things have changed. Shamsaei et al (2015:1) affirm that these cyclic occurrences affect the individual and social development plans. Most young people in the study further revealed that the situation overwhelmed them to such an extent that their school work and progress was affected. As a result, they were faced with repeating grades and being old for grades.

### **5.3.3 Effects on schooling performance**

Unsatisfactory progress is a symptom that reflects an underlying difficulty (Burn & Roos 2016:496). The findings of this study revealed that most of the participants were old for their grade as evidenced by several repeats of the grades. Participants were between the ages of 21-23 years old and still at high school. This was due to periodically missing class and under-preparedness for class work, tests and examinations. Cooklin (2013:229) and Boursnell (2014:96) revealed similar findings.

The findings of this study highlighted that young people living with MHCUs were faced with poor academic progress, which leads to inability to cope, and indulging in alcohol and substance abuse, resulting in these young people dropping out from school (Ebersöhn, Gouws, Lewis & Theron 2015:163). According to Bjorgvinsdottir and Halldorsdottir (2014:43), young people dropped out from the school because of the demanding duties at home. The effects of poor academic performance and progress, as well as dropping out, may cause the young people to face poverty, unemployment and an inability to compete with peers in future.

It became evident in this study that young people depended on the social grants of their MHCUs because most of them were high school students. It was further revealed that most of the young people were living in impoverished conditions. Fernqvist

(2015:219), who found that young people face lowered standards of living and financial hardships, revealed similar findings.

#### **5.3.4 Coping and support system needs**

Coping refers to cognitive and behavioural efforts aimed at mastering environmental stressors and challenges. It includes any response to external life strain that serves to prevent, avoid or control emotional distress and keep an individual away from the damage from life strains (Marimbe et al 2016:2; Uys & Middleton 2014:196). Besides dealing with stressful daily living with the MHCUs, the study findings reveal that participants experienced aggravating conditions such as stigmatisation, social exclusion, family disruptions, and lack of resources in the care giving process.

The study highlighted that young people living with MHCUs dealt with stigmatisation, misunderstanding of illness aetiology, strained family and community relationships, and social exclusion. A study on exploring the stigma related experiences of family members affirm that the family was mocked and ridiculed and treated in an unusual way because of living with MHCUs (Nxumalo & Mchunu 2017:209). Marimbe et al (2016:5) identify that families caring for a MHCUs are exposed to a lot of stigma due to a lack of knowledge from the community and other relatives, and were ostracised and isolated. The study further revealed family disruptions such as lowered family cohesion, chaotic home environments, poorer communication, parent-child discord, and a lack of parental support required to achieve competencies and models in handling interpersonal conflict. These findings are supported by numerous studies (Monyaluoe, Mvandaba, Plessis & Koen 2014:5; Lander, Howsare & Byrne 2013:200; Van Loon et al 2014:1201; Katz et al 2015:787).

The findings of this study affirm that young people experienced a lack of resources, socioeconomic stress and poverty, financial/material support, and lack of knowledge about mental illness. Similar findings were found in the studies of Jeyagurunathan et al (2017:2) and Trondsen (2012:178), and they affirm that families living with MHCUs experience a lack of knowledge, financial difficulties, and lower life satisfaction. Ola et al (2015:76) and Bjorgvinsdottir and Halldorsdottir (2014:41) emphasise that a lack of

adequate knowledge sustains deep-seated negative attitudes towards mental illness and feelings of anxiety and denial in the lives of young people.

This study revealed different ways that were used by young people living with MHCUs in order to manage stressful experiences with the MHCU parent or relative. Unhealthy defence mechanisms applied included suppression, withdrawal and denial. Uys and Middleton (2014:28) describe unhealthy defence mechanisms as cognitive patterns that negatively influence a person's adaptation. The study findings revealed that young people resorted to the use of alcohol and smoking dagga to escape their living situation with MHCUs. In a study on the experiences of adolescents dealing with social and emotional problems in high school, Mfidi (2016:123) affirms that most school-going adolescents use alcohol and drugs to handle difficult situations. This negative behaviour is referred to as 'drinking in order to cope', which has negative outcomes for the individual's social and emotional well-being. It also further exacerbates the person's problems to other risk factors like involvement in fights, high risk of sexual behaviours, and suicidal ideation and behaviours. The findings in this study revealed that participants ignore or withdraw as avoidance strategies to control and contain the situation during times of relapse and destructive behaviours of MHCUs. The continual use of these defence mechanisms further increases the mental distress instead of lessening the problem and experiences, as evidenced in this study by participants reporting an inability to concentrate at school, hence, their school performance and progress were adversely affected.

Conversely, several authors such as Dam and Hall (2016:453), Trondsen (2012:182) and Azman et al (2017:101), concur that establishing physical and emotional distance during relapse periods could have positive outcomes of lessening the stress. This could be effected by engaging in activities like doing exercises, going on vacation, watching television, and praying. In these study findings, socio-cultural practices were identified as fostering positive effects and understanding of the situation, and thus buffer the stress levels of living with MHCUs. These included attending church rituals, called '*ditaelo*'. Cultural practices have also been described as strategies such as families living with MHCUs consulting traditional healers and faith healers to allay anxiety and to manage MHCUs' symptoms (Marimbe et al 2016:5).

## **5.4 CONCLUSION**

These findings seek to support and concur with numerous existing empirical evidence on the experiences of family members, which include young people living with MHCUs. On a similar note, these study findings concur with reports that children and young people with mentally ill parents are more likely to show lower academic competence and difficulty with social relationships (Cooklin 2013:229; McCann et al 2015:206).

Young people living with mentally ill parents or relatives dealt with physical, psychological, social and economic challenges. Living with a MHCU has been shown to be a miserable life, a significant caring burden, and the cause for feelings of despondency. Young people lived with fear and guilt due to behavioural manifestations displayed by MHCUs (Monyaluoe et al 2014:5). These exposed their lives to dangerous risks.

Most of the young people provided difficult and demanding care to MHCUs without the support of family members, their community and professionals, and without knowledge with regard to the nature of mental illness. As a result, some of the young people were not coping with the situation.

## **5.5 RECOMMENDATIONS**

It became apparent in this study that young people living with MHCUs experienced various challenges in all spheres of their lives. Based on these results, the researcher makes the following recommendations.

### **5.5.1 Psychiatric nursing practice**

- Periodical visits by community psychiatric nurses in the homes of discharged MHCUs.
- Psycho-educational programmes in schools to empower school-going young people with knowledge on diagnosis, aetiology, signs and symptoms, and the management of mental illness.

- Creation of support groups for young people living with MHCU parents or relatives.
- Multidisciplinary team involvement and collaboration to identify needs and to support families living with MHCUs.
- Continuous mental health/mental illness awareness campaigns in schools and communities.

### **5.5.2 Community psychiatric services**

- Involvement of all family members, including young people, in the preparation of MHCUs for discharge.
- Burden-sharing or a relief system for young people who are sole caregivers of MHCUs. Motivate for respite care in 24-hour primary health care clinics in times of need, such as exam times, to ensure school progress.
- Day-care rehabilitation programmes at the nearby clinics to keep the MHCUs occupied.

### **5.5.3 Further research**

- This has been a cross-sectional study focusing on late adolescence. Further longitudinal research is recommended to explore the effects of living with MHCUs from early adolescence until later periods so as to relate earlier experiences with the later developmental effects in adulthood.
- A comparative study on how the psychiatric community health services of different provinces of South Africa deal with the needs of young people living with MHCUs is recommended.

## **5.6 CONTRIBUTIONS OF THE STUDY**

The study findings yielded insight into what young people living with MHCUs are faced with challenges in their daily life experiences and thus pose a challenge to health professionals, researchers, family and community dealing with young people to take cognisance of the support needs of young people living with MHCUs. The recommendations made based in this study will influence programme planners in the community health centres, school health services and community at large in ensuring that coping and support systems for young people living with MHCUs are maximised, thus promoting their quality of life. The study will also add to the body of knowledge regarding how mental illness in the family affect social functioning of the family and its members.

## **5.7 LIMITATION OF THE STUDY**

Since the qualitative research method was used, the results cannot be replicated (Parahoo 2014:273). This study is only limited to one area of the province and a small sampling of 10 participants were used. Thus, this study cannot be generalised. Non-probability sampling was used in the study; purposive sampling was used instead of random selection of participants. The study concentrated only on young people between the ages of 19-23 years living with MHCUs.

## **5.8 CONCLUDING REMARKS**

Living with MHCUs has been shown to lead to severe psychological effects, lack of socialisation with peers, isolation, dangerous risks, academic difficulty and uncertainty for the future of young people.

## REFERENCES

- Ae-Ngibise, KA, Doku, VCK, Asante, KP & Owusu-Agyei, S. 2015. The experience of people living with serious mental disorders: A study from rural Ghana. *Global health action*, 8:26957.
- Abram, KM & Stein, CH. 2013. When mom has a mental illness: Role reversal and psychological adjustment among emerging adults. *Journal of clinical psychology*, 69(6):600-615.
- Azman, A, Singh, PSJ & Sulaiman, J. 2017. Caregiver coping with mental ill: a qualitative study. *Journal of mental health*, 26(2):98-103.
- Bessa, JP & Weidman, MAP. 2013. Family of people with mental disorder and needs in psychiatric care. *Texto context Enferm, Florianópolis*, 22(1):61-70.
- Bjorgvinsdottir, K & Halldorsdottir, S. 2014. Silent, invisible and unacknowledged: experiences of young caregivers of single parents diagnosed with multiple sclerosis. *Scandinavian Journal of Caring Sciences*, 28:34-48.
- Bland, R & Foster, M. 2012. Families and mental illness: Contested perspective and implications for practice and theory. *Australian social work*, 65(4):514-534.
- Botha, UA, Koen, L, Joska, JA, Parker, JS, Horn, N, Hering, LM, Oosthuizen, PP. 2010. The revolving door phenomenon in psychiatry: Comparing low-frequency and high-frequency users of psychiatric inpatient services in a developing country. *Social psychiatry epidemiology*, 45:461-468.
- Boursnell, M. 2014. Assessing the capacity of parents with mental illness and risk. *International social work*, 57(2):92-108.
- Brink, H, Van der Walt, C & Van Rensburg, G. 2012. *Fundamentals of research methodology for healthcare professionals*. 3<sup>rd</sup> edition. Cape Town: Juta & Company.

Brook-Sumner, C, Lund, C & Peterson, I. 2014. Perceptions of psychosocial disability amongst psychiatric service users and caregivers in South Africa. *Journal of disability*, 3(1):1-10.

Burn, J & Roos, L. 2016. *Textbook of psychiatry for Southern Africa*. 2<sup>nd</sup> edition. Cape Town: University Press.

Chang, S, Zhang, Y, Jeyaguruna, A, Lau, YW, Sagayadevan, V, Chong, SA & Subramaniam, M. 2016. Providing care to relatives with mental illness: reactions and distress among primary care givers. *BMC psychiatry*, 16:80.

Clarke, M. 2016. *Vlok's community health*. 6<sup>th</sup> edition. Cape Town: Juta & company Ltd.

Cooklin, A. 2013. Promoting children's resilience to parental mental illness: Engaging the child's thinking. *Advances in psychiatric treatment*, 19:229-240.

Creswell, JW. 2014. *Research design. Qualitative, quantitative and mixed methods approaches*. 4<sup>th</sup> edition. California: Sage publications, Inc.

Dam, K & Hall, EOC. 2016. Navigating in an unpredictable daily life: A metasynthesis on children's experiences living with a parent with severe mental illness. *Scandinavian journal of caring sciences*, 30:444-457.

De Beer, J & Brysiewicz, P. 2017. The experiences of family members during the critical illness of a loved one admitted to an intensive care unit. *Africa Journal of Nursing and Midwifery*, 19(1):56-68.

De Vos, AS, Strydom, H, Fouché, CB & Delport, CSL. 2011. *Research at grass roots for the social sciences and human service professions*. 4<sup>th</sup> edition. Pretoria: Van Schaik.

Ebersöhn, L, Gouws, E, Lewis, A & Theron, L. 2015. *The adolescent*. 4<sup>th</sup> edition. Cape Town: Pearson Holdings South Africa (Pty) Ltd.



Engelbrecht, C & Kasiram, MI. 2012. The role of Ubuntu in families living with mental illness in the community. *South African family practice*, 54(5):441-446.

Fernqvist, S. 2015. Negotiating parenthood: experiences of economic hardship among parents with cognitive difficulties. *Journal of intellectual disabilities*, 19(3):215-229.

Foster, K, O'Brien, L & Korhonen, T. 2012. Developing resilient children and families when parents have mental illness: A family-focused approach. *International Journal of mental health nursing*, 21:3-11.

Grove, K, Gray, JR & Burns, N. 2015. *Understanding nursing research*. Building an evidence-based practice. 6<sup>th</sup> edition. ST Louis: Elsevier Saunders.

Homlong, L, Rosvold, EO, Sagatun, A, Wentzel-Larsen, T & Haavet, OR. 2015. Living with mentally ill parents during adolescence: a risk factor for future welfare dependence? A longitudinal, population-based study. *BMC Public health*, 15(413):1-10.

Huang, H, Jen, Y & Lien, Y. 2016. Stigma experienced by caregivers of patients with schizophrenia: a qualitative study. *International journal of nursing and clinical practice*, 3:182.

Hutchinson, K, Roberts, C, Skurrlle, S & Daly, M. 2016. The emotional wellbeing of young people having a parent with younger onset of dementia. *Dementia*, 15(4): 609-628.

Iseselo, MK, Kajula, L & Yahya-Malima, KI. 2016. The psychosocial problems of families caring for relatives with mental illness and their coping strategies. *BMC psychiatry*, 16:146.

Jeyagurunathan, A, Sagayadevan, V, Abidin, E, Zhang, Y, Chang, S, Shafie, S, Rahman, RFA, Vaingakar, JV, Chong, SA & Subramaniam, M. 2017. Psychological status and caregivers of individuals with mental illness: a hospital based study. *Health and quality of life outcomes*, 15:106.

Karnieli-Miller, O, Perlick, DA, Nelson, A, Mattias, K, Corrigan, P & Roe, D. 2013. Family members of persons living with serious mental illness: Experiences and efforts to cope with stigma. *Journal of mental health*, 22(3):254-262.

Katz, J, Medoff, D, Fang, LJ & Dixon, LB. 2015. The relationship between the perceived risk of harm by a family member with mental illness and the family experience. *Community mental health journal*, 51(7):790-799.

Kontio, R, Lantta, T, Anttila, M, Kauppi, K & Välimäki, M. 2017. Family involvement in managing violence of mental health patients. *Perspective in psychiatric care*, 53:55-66.

Koschorke, M, Padmavati, R, Kumar, S, Cohen, A, Weiss, HA, Chatterjee, S, Pereira, J, Naik, S, John, S, Dabholka, H, Balaji, M, Chavan, A, Varghese, M, Thora, R, Patel, V & Thornicroft, G. 2017. Experiences of stigma and discrimination faced by family caregivers of people with schizophrenia in India. *Social science and medicine*, 178:66-77.

Lander, L, Howsare, J & Byrne, M. 2013. The impact of substance use disorders on families and children: From theory. *Social Work Public Health*, 28(0):194-205.

Lauritzen, C, Reedtz, C, Van Doesum, K & Martinussen, M. 2015. Factors that facilitate or hinder a family- focus in the treatment of parents with a mental illness. *Journal of Child and Family study*, 24:864-871.

Leahy, MA. 2015. Children of mentally ill parents: understanding the effects of childhood trauma as it pertains to the school setting. *International journal of educational research*, 71:100-107.

Lippi, G. 2016. Schizophrenia in a member of the family: Burden, expressed emotion and addressing the needs of the whole family. *South African journal of psychiatry*, 22(1): a922.

LoBiondo-Wood, G & Haber, J. 2014. *Nursing research*. Methods and critical appraisal for evidence-based practice. 8<sup>th</sup> edition. Missouri: Mosby Inc.

Mackenzie, J. 2014. Global mental health from a policy perspective: A context analysis. *Mental health innovation network*.

Magadla, MW & Magadla, NI. 2014. Effects of mental illness on relationship amongst families, relative and friends with mentally ill persons. *African Journal for Physical Health Education, Recreation and Dance*, 3:126-135.

Malhotra, M. 2016. Burden among caregivers of mentally ill patients: A Review. *International Journal of multidisciplinary and current research*, 4.

Marais, DL & Petersen, I. 2015. Health system governance to support integrated mental health care in South Africa: challenges and opportunities. *International Journal of mental health support system*, 9(14).

Marimbe, BD, Cowan, F, Kajawu, L, Muchirahondo, F & Lund, C. 2016. Perceived burden of care and reported coping strategies and needs for caregivers of people with mental disorders in Zimbabwe. *African Journal of Disability*, 5(1):9209.

Mavundla, TR, Toth, F & Mphelane, ML. 2009. Caregiver experience in mental illness: A perspective from a rural community in South Africa. *International Journal of mental health in nursing*, 18:357-367.

McCann, TV, Bamberg, J & McCann, F. 2015. Family carers' experience of caring for older parents with severe and persistent mental illness. *International journal of mental health nursing*, 24:203-212.

Mechling, BM. 2011. The experiences of youth serving as caregivers for mentally ill parents. *Journal of psychosocial nursing*, 49(3).

Mfidi, FH. 2016. Promotion of adolescent mental health through a social and emotional learning programme in South African high schools. *University of South Africa*. Pretoria.

Miller-Slough, RL & Dunsmore, JC. 2016. Parent-friend emotion socialisation in Adolescence: Associations with psychological Adjustment. *Adolescent Research Review*, 1(4):287-305.

Mills, J & Birks, M. 2014.*Qualitative methodology*. A practical guide. London: SAGE Publications.

Mizuno, E, Takataya, K, Kamizawa, N, Sakai, I & Yamazaki, Y. 2013.Female families' experiences of caring for persons with schizophrenia. *Archives of psychiatric nursing*, 27:72-77.

Moule, P & Goodman, M. 2014.*Nursing research*. An introduction.2<sup>nd</sup> edition. California: SAGE Publications Ltd.

Monyaluoe, M, Mvandaba M, Plessis, ED & Koen, MP. 2014. Experiences of families living with a family member. *Journal of Psychiatry*, 17(5):131.

Munhall, PL. 2012.*Nursing research: A qualitative perspective*. 5<sup>th</sup> edition. Sudbury, MA: Jones & Bartlett learning.

Muralidharan, A, Lucksted, A, Medoff, D, Fang, LJ & Dixon, L. 2016. Stigma: a unique source of distress for family members of individuals with mental illness. *Journal of behavioural health services and research*, 43(3):484-493.

Nxumalo, CT & Mchunu, GG. 2017. Exploring the stigma related experiences of family members of persons with mental illness in a selected community in the iLeme district, Kwa Zulu Natal. *Health SA Gesondheid*, 22:202-212.

Ola, B, Suren, R & Ani, C. 2015. Depressive symptoms among children whose parents have serious mental illness: association with children 's threat- related beliefs about mental illness. *South African journal of psychiatry*, 21(3):74-78.

Oxford Advanced Learner's Dictionary. 2010. 8<sup>th</sup> edition. Oxford University Press: New York.

Parahoo, K. 2014. *Nursing research, principles process and issues*. 3<sup>rd</sup> edition. Basingstoke: Palgrave Macmillan Publisher.

Polit, DF & Beck, CT. 2012. *Nursing research. Generating and Assessing evidence for nursing practice*. 9<sup>th</sup> edition. Philadelphia: Wolters Kluwer/ Lippincott Williams & Wilkins.

Polit, DF & Beck, CT. 2014. *Essentials of nursing research*. Appraising evidence for nursing practice. 8<sup>th</sup> edition. Philadelphia: Wolters Kluwer health/ Lippincott Williams & Wilkins.

Pusey-Murray, A & Miller, P. 2013. I need help: caregivers' experiences of caring for their relatives with mental illness in Jamaica. *Mental health in family medicine*, 10:113-121.

Radfar, M, Ahmadi, F & Khoshkhab, MF. 2013. Turbulent life, the experiences of the family members of patients suffering from depression. *The Journal of psychiatric and mental health nursing*.

Reupert, AE. & Mayberry, DJ. 2010. Knowledge is Power: Educating Children about Their Parent's Mental Illness. *Social Work in Health Care*, 49(7):630-646.

Reupert, AE & Maybery, DJ. 2016. What do we know about families where parents have mental illness? A systemic review. *Child and youth services*, 37(2):98-111.

Reupert, AE, Maybery, DJ & Kowalenko, NM. 2012. Children whose parents have a mental illness: prevalence and treatment. *Clinical focus MJA open1 suppl 1*.

Rogers, EB, Stanford, M & Garland, DR. 2012. The effects of mental illness on families within faith communities. *Mental health, religion and culture*, 15(3):301-313.

Rose, HD & Cohen, K. 2010. The experiences of young carers: A meta-synthesis of qualitative findings. *Journal of Youth Studies*, 13(4):73-487.

Rossen, CB, Stenager, E & Buus, N. 2014. The experiences of being close relatives and informal carers of mentally ill Iraq refugees: A qualitative study. *International journal of culture and mental health*, 7(4):452-463.

Saks, M & Allsop, J. 2013. *Researching health. Qualitative, Quantitative and mix method*. 2<sup>nd</sup> edition. London: SAGE publications.

Sanders, A, Szymanski, K & Fiori, K. 2014. The family roles of siblings of people diagnosed with mental disorder: Heroes and lost children. *International journal of psychology*, 49(4):257-262.

Sewilam, AM, Watson, AM, Kassem, AM, Clifton, S, Mc Donald, MC, Lipski, R, Deshpande, S, Mansour, H & Nimgaonkar, VL. 2015. Suggested avenues to reduce the stigma of mental illness in the Middle East. *International social psychiatry*, 61(2):111-120.

Shamsaei, F, Cheraghi, F & Esmaeilli, R. 2015. The family challenge of caring chronically mentally ill. *Iran Journal Psychiatry Behavioral Sciences*, 9(3): e1898.

South Africa. 1996. *The Constitution of Republic of South Africa*, Act no.108 of 1996. Pretoria: Government.

South Africa. 1997a. *National health policy guideline for improved mental health in South Africa*. Pretoria: Government printer.

South Africa. 1997b. *White paper for the transformation of the health system in South Africa*. Pretoria: Government printer.

South Africa. 2002. *Mental Health Act 17 of 2002*. Pretoria: Government Printer.

Sporer, K & Toller, PW. 2017. Family identity disrupted by mental illness and violence. *An application of relational dialectics theory*, 82(2):85-101.

Stein, DJ. 2014. A new mental health policy for South Africa. *South African Medical Journal*, 104(2):115-116.

Streubert, HJ & Carpenter, DR. 2011. *Qualitative research in nursing*. Advancing the humanistic imperative. 5<sup>th</sup> edition. Philadelphia: Wolters Kluwer health/Lippincott Williams & Wilkins.

Tan, CH, Yeoh, AL, Choo, IBK, Huang, APH, Ong, SH, Ismail, H, Ang, PP & Chang, YH. 2012. Burden and coping strategies experienced by caregivers of persons with schizophrenia in the community. *Mental health Journal of clinical nursing*, 21(17-18):2410-2418.

Tlhowe, TT, Du Plessis, E & Koen, MP. 2017. Strength of families to limit relapse in mentally ill family member. *Heath SA gesondheid*, 22:28-35.

Townsend, MC. 2015. *Psychiatric mental health nursing, concepts of care in evidence-based practice*. 8<sup>th</sup> edition. Philadelphia: FA Davis Company.

Trondsen, M. 2012. Living with a mentally ill parent: Exploring adolescents' experiences and perspective. *Qualitative health research*, 22(2):174-188.

UNESCO. 2015. *Education for all global monitoring report*. United Nation: UNESCO Publishing.

Uys, L & Middleton, L. 2014. *Mental health nursing, a South African perspective*. 6<sup>th</sup> edition. Cape Town: Juta & Company.

Van Loon, LMA, Van de Ven, MOM, Van Doesum, KTM, Witteman, CLM & Hosman, CMH. 2014. The relation between parental mental illness and adolescent mental health: The role of family factors. *Journal of family study*, 23:1201-1214.

Venkatesh, BT, Andrews, T, Parsekar, SS, Singh, MM & Menon, N. 2016. Stigma and mental health-care givers' perspective. *Clinical epidemiology and global health*, 4(1):23-27.

Verrochio, MC, Abrosini, A & Fulcheri, M. 2013. Promotion of mental health in children of parents of mental disorder. *Annist super sanità*, 49(4):406- 411.

Weimand, BM, Hall-Lord, ML, Sällström, C & Hedelin, B. 2013. Life-sharing experiences of relatives of persons with severe mental illness. *Scandnavian journal of caring sciences*, 27:99-101.

Winther-Lindquist, DA. 2014. Uncertainty as organizing principle of action. Teenage living with parental somatic illness. *Illness, crisis and loss*, 22(2):95-113.

Wittenburg, E, Saada, A & Prosser, LA. 2014. How illness affects family members a qualitative interview survey. *NIH Public Access*.

WHO. 2007. *Integrating mental health services into primary health care*. Geneva: Government Printer.

WHO. 2007. *WHO Aims report on mental health system in South Africa*. Pretoria: Government Printer.

WHO. 2013. *European mental health action plan*. 2013-2020. Europe: Government printer.

WHO. 2013. *National mental health policy framework and strategic plan 2013-2020*. Pretoria: Government Printer.



## **ANNEXURE A: INFORMED CONSENT FORM OF THE PARTICIPANTS**

**Study Title:** LIVED EXPERIENCES OF YOUNG PEOPLE LIVING WITH MENTAL HEALTH CARE USERS IN LIMPOPO PROVINCE

### **INFORMATION SHEET AND CONSENT FORM**

My name is Molepo Mamokota Maggie and I am currently doing Masters in Nursing with Department of Health Studies at the University of South Africa. I am also a professional nurse and conducting a research study on the lived experiences of young people living with mental healthcare users in Limpopo Province.

#### **Your participation**

I am requesting your permission to take part in a single interview about your experiences in your daily life, living with mental healthcare users. You will be interviewed alone (individual interview) for about 30-45 minutes. I am requesting your permission to tape record the interview so that the information you share can be accurately captured.

Taking part in this study will be through your free will, that is, you must want to take part (voluntary). No one will force you or punish you if you do not want to take part. If you do not wish to take part, you are not to give any reasons for not taking part. Even if you agree and as we continue with the interview, you feel you do not want to continue you may do so too.

The researcher does not foresee any harm in taking part in this study. But if whilst we are continuing with the interviews you feel uncomfortable with answering some questions or rather want to withdraw from the study, you can tell the researcher and your wish will be respected without any penalty. The researcher has also arranged with the clinic psychologist to assist if there could be any emotional discomfort you experience. The clinic psychologist will help to calm you down and let you talk about the discomforting issues so that you can feel better (psychological counselling and debriefing).

All the information that you share during the interview will not have your name attached but a code will be used to differentiate you from the other participants and the information you share will be kept in the locked cupboard.

For any questions you may have at any stage or during the study process, feel free to contact me: Ms Molepo at 0725943181 and research supervisor 012-4296731.

If you are satisfied and agree to be part of the study, please fill in and sign consent form below.

**Consent document:**

I..... have read and understood the information entailed in the letter, requesting my consent to participate in this study entitled: **Lived experiences of young people living with mental healthcare users in Limpopo province** . I therefore attach my signature as a sign of my willingness to voluntarily participate in the abovementioned study.

Signed at..... on this..... day  
of.....2017

Participant signature..... Researcher signature  
.....

Thanking you in anticipation.

## ANNEXURE B: IN-DEPTH INTERVIEW GUIDE

### A. DEMOGRAPHIC DATA

#### Participant Information

1. **Age:** ☐ <18yrs ☐ 19-21 ☐ 22-24
2. **Family members ( state the no):** ☐ Mother ☐ Father ☐  
Brother/s ☐ Sister/s ☐ other /please specify: \_\_\_\_\_
3. **Hobbies:** ☐ Sporting ☐ Listen to Music ☐ other /please  
specify: \_\_\_\_\_
4. **Friendship:** ☐ at school ☐ in the community ☐ other /please  
specify: \_\_\_\_\_
5. **Level of Previous Education:** ☐ Primary ☐ Secondary ☐  
Tertiary
6. **Highest Qualification gained:** - \_\_\_\_\_
7. **Occupational status of Participant.**  
Unemployed ☐ Self-Employed ☐ Employed ☐  
Job title (if employed): - \_\_\_\_\_

### B. Interview Guide

#### INTERVIEW GUIDE

Researcher will ask three broad or central open ended questions and the responses of the participants will generate other questions. Probing will be done to increase detailed exploration from the participants.

- How will you describe your experience of living with a mentally ill relative?
- What are coping strategies used by young people living with mental health users?
- What are the needs of young people living with mental healthcare use?

## ANNEXURE C: ETHICAL CLEARANCE CERTIFICATE FROM UNISA



**RESEARCH ETHICS COMMITTEE: DEPARTMENT OF HEALTH STUDIES**  
**REC-012714-039 (NHERC)**

1 March 2017

Dear MS MM Molepo

**Decision: Ethics Approval**

**HS HDC/663/2017**

MS MM Molepo

Student: 3112-548-4

Supervisor: Dr FH Mfidi

Qualification: D Litt et Phil

Joint Supervisor: -

**Name:** MS MM Molepo

**Proposal:** Lived experiences of young people living with mental health care users in Limpopo Province.

**Qualification:** MPCHS94

Thank you for the application for research ethics approval from the Research Ethics Committee: Department of Health Studies, for the above mentioned research. Final approval is granted for the duration of the research period as indicated in your application.

*The application was reviewed in compliance with the Unisa Policy on Research Ethics by the Research Ethics Committee: Department of Health Studies on 1 March 2017.*

*The proposed research may now commence with the proviso that:*

- 1) The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.*
- 2) Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Research Ethics Review Committee, Department of Health Studies. An amended application could be requested if there are substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.*

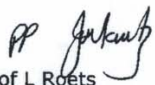
3) The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study.

4) [Stipulate any reporting requirements if applicable].

**Note:**

The reference numbers [top middle and right corner of this communiqué] should be clearly indicated on all forms of communication [e.g. Webmail, E-mail messages, letters] with the intended research participants, as well as with the Research Ethics Committee: Department of Health Studies.

Kind regards,

  
Prof L Roets  
CHAIRPERSON  
[roetsl@unisa.ac.za](mailto:roetsl@unisa.ac.za)

  
Prof MM Moleki  
ACADEMIC CHAIRPERSON  
[molekmm@unisa.ac.za](mailto:molekmm@unisa.ac.za)

## **ANNEXURE D: LETTER OF REQUEST TO DEPARTMENT OF HEALTH LIMPOPO**

Department of Health

18 College Street

Private Bag X9302

Polokwane

0700

Dear sir/ Madam

My name is Mamokota Maggie Molepo and I am a registered Masters student in the Department of Health Studies at the University of South Africa. I am hereby seeking your consent to conduct research on official working hours in Dikgale area Limpopo province. This project will be conducted under the supervision of Dr FH Mfidi. The proposed topic of my research is: 'Lived experiences of young people living with mental healthcare users in Limpopo province.'

The objectives of the study are:

- (a) To describe the lived experiences of young people living with mental healthcare users
- (b) To determine the coping strategies of young people living with mental healthcare users
- (c) To make recommendations on mechanism to support young people living with mental healthcare users.

To assist you in reaching a decision, I have attached to this letter a copy of my research proposal and consent forms to be used in the research process, as well as a copy of the approval letter which I received from UNISA Research Ethics Committee.

Upon completion of the study, I undertake to provide the Department of Health with a bound copy of the full research report.

Should you require any further information, please do not hesitate to contact me or my supervisor? Our contact details are as follows:

Cell: 0725943181

Tel no: 012-4296731

Tel: 0152671114

Fax: 012-4296688

E-mail: [mamokota@webmail.co.za](mailto:mamokota@webmail.co.za)

[Mfidifh@unisa.ac.za](mailto:Mfidifh@unisa.ac.za)

Student contact details Supervisor's contact details

Your permission to conduct this study will be greatly appreciated.

Yours sincerely,

Mamokota Maggie Molepo

## ANNEXURE E: PERMISSION LETTER FROM DEPARTMENT OF HEALTH



**LIMPOPO**  
PROVINCIAL GOVERNMENT  
REPUBLIC OF SOUTH AFRICA

### DEPARTMENT OF HEALTH

Enquiries: Latif Shamila (015 293 6650)

Ref:4/2/2

**Molepo MM**  
**UNISA**

Greetings,

**RE: Lived experiences of young people living with Mental Health Care Users in Limpopo Province**

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
  - Research must be loaded on the NHRD site (<http://nhrd.hst.org.za>) by the researcher.
  - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
  - In the course of your study there should be no action that disrupts the services.
  - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
  - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
  - The above approval is valid for a 3 year period.
  - If the proposal has been amended, a new approval should be sought from the Department of Health.
  - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

7   
Head of Department

10.05.2017  
Date



## **ANNEXURE F: LIMPOPO LETTER OF REQUEST PHC DISTRICT OFFICE**

Deputy Nursing Director - Primary Health Care

Private Bag X9530

Polokwane

Dear sir/ Madam

My name is Mamokota Maggie Molepo and I am a registered Masters student in the Department of Health Studies at the University of South Africa. I am hereby seeking your consent to conduct research on official working hours in Dikgale area Limpopo province. This project will be conducted under the supervision of Dr FH Mfidi. The proposed topic of my research is: 'Lived experiences of young people living with mental healthcare users in Limpopo province.'

The objectives of the study are:

- (a) To describe the lived experiences of young people living with mental healthcare users
- (b) To determine the coping strategies of young people living with mental healthcare users
- (c) To make recommendations on mechanism to support young people living with mental healthcare users.

To assist you in reaching a decision, I have attached to this letter a copy of my research proposal and consent forms to be used in the research process, as well as a copy of the approval letter which I received from UNISA Research Ethics Committee.

Upon completion of the study, I undertake to provide the Department of Health with a bound copy of the full research report.

Should you require any further information, please do not hesitate to contact me or my supervisor. Our contact details are as follows:

Cell: 0725943181

Tel no: 012-4296731

Tel: 0152671114

Fax: 012-4296688

E-mail: [mamokota@webmail.co.za](mailto:mamokota@webmail.co.za)

mfidi@unisa.ac.za

Student contact details

Supervisor's contact details

Your permission to conduct this study will be greatly appreciated.

Yours sincerely,

Mamokota Maggie Molepo

## ANNEXURE G: PERMISSION LETTER FROM PHC DISTRICT OFFICE



# LIMPOPO

PROVINCIAL GOVERNMENT  
REPUBLIC OF SOUTH AFRICA


### DEPARTMENT OF HEALTH CAPRICORN DISTRICT

**Enq** : Malema DMM  
**Tel** : 015 290 9266  
**From** : Primary Health Care  
**Date** : 15 May 2017  
**To** : Molepo MM  
UNISA  
**Subject** : Lived experiences of young people living with Mental Health Care  
Users in Limpopo Province  
**Cc** : Assistant Managers Polokwane East Clinics

The above matter refers

1. Permission to conduct the above mentioned research is hereby granted.
2. Kindly be informed that :
  - In the course of your research there should be no action that disrupts the services.
  - After completion of the study, it is mandatory that the findings should be submitted to the Department of serve as a resource.
  - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
  - Kindly note, that the Department can withdraw the approval at any time

Your cooperation will be highly appreciated.

  
.....  
Acting Director PHC

2017 05 15  
.....  
Date

## **ANNEXURE H: LETTER OF REQUEST TO DIKGALE TRIBAL AUTHORITY**

The Secretary

Dikgale Tribal Authority

Ga Dikgale

0721

Dear sir/ Madam

My name is Mamokota Maggie Molepo and I am a registered Masters student in the Department of Health Studies at the University of South Africa. I am hereby seeking your consent to conduct research on official working hours in Dikgale area Limpopo province. This project will be conducted under the supervision of Dr FH Mfidi. The proposed topic of my research is: 'Lived experiences of young people living with mental healthcare users in Limpopo province.'

The objectives of the study are:

- (a) To describe the lived experiences of young people living with mental healthcare users
- (b) To determine the coping strategies of young people living with mental healthcare users
- (c) To make recommendations on mechanism to support young people living with mental healthcare users.

To assist you in reaching a decision, I have attached to this letter a copy of consent forms to be used in the research process, as well as a copy of the approval letter which I received from the Province Research Ethics Committee and from Primary Health Care.

Upon completion of the study, I undertake to provide the Department of Health with a bound copy of the full research report.

Should you require any further information, please do not hesitate to contact me or my supervisor. Our contact details are as follows:

Cell: 0725943181

Tel no: 012-4296731

Tel: 0152671114

Fax: 012-4296688

E-mail: [mamokota@webmail.co.za](mailto:mamokota@webmail.co.za)

Mfidi@unisa.ac.za

Student contact details Supervisor's contact details

Your permission to conduct this study will be greatly appreciated.

Yours sincerely,

Mamokota Maggie Molepo

## ANNEXURE I: PERMISSION LETTER FROM DIKGALE TRIBAL AUTHORITY



P.O. BOX 57  
DIKGALE  
0721

Enquiries : Mabitsela M.J.  
Contact No : 073 749 3515

2018-03-20



### TO WHOM IT MAY CONCERN

### PERMISSION TO CONDUCT A RESEARCH IN DIKGALE AREAS

Dear Sir/Madam

We have given Mamokota Maggie Molepo ID No: 6403190341081 permission and approval to conduct a research in Dikgale Area from the 18<sup>th</sup>/06/2017 to the 20<sup>th</sup>/07/2017.

Hoping for a better consideration.

  
\_\_\_\_\_  
Mathipa.R.F. Secretary

## **ANNEXURE J: INTERVIEW TRANSCRIPTS**

### **LIVED EXPERIENCES OF YOUNG PEOPLE LIVING WITH MENTAL HEALTH CARE USERS IN LIMPOPO PROVINCE**

#### **Participant no 1: 21 years' male- Father mentally ill since he was born**

During 2015 my father started to talk things that do not exist, such as somebody want to kill me, shouting and talking on the street.

I was afraid to go outside and I felt bad.

My father destroyed other people's properties and my mother asked me to go and fix to those broken properties to the neighbours.

When I was there to fix the broken properties, the women of that house was very angry with me and talk bad things to me.

My mother is the one who is supervising my father with taking of treatment.

I am helping my father with taking care of animals because he likes animals.

#### **Coping strategies**

I am patient with my father when he is talking alone, because if I become impatient with him he started making a lot of noise.

Do not be impatient with a mentally ill person because he can injure you or other people on the street.

My mother, my grandmother and my other brothers are helping in taking care of my father

#### **Income**

My father is getting social grant.

My brothers are doing piece jobs and my mother is getting children support grant for grand children

**Needs-** None

**Participant 2: 19 years female- mother MHCU since she was born**

I felt bad I felt bad. I was not thinking that my mother can be mentally ill.

When my mother is ill the family becomes disrupted.

I cannot even concentrate in class.

I sleep in class, and I hesitate to come home after school.

When my mother is sick she break windows, bathing basins, chasing people on the street, shouting and singing on the street, switching off the stoves when we are trying to cook.

Standing in front of the moving cars and getting inside of the bus without knowing where she is going.

When my mother is sick I call the police to come and help us.

I am helping my mother with taking of medication.

**Coping strategies**

It is tough because sometimes I am thinking about my mother that what if my mother started to be ill during my examination. What am I going to do? I am not coping. I pretend as if I am coping but deep down I am feeling pain.

**Support**

Neighbours are just watching and laughing without helping us, but sometimes my mother is brought by a stranger at home. My grandmother and father are giving us support

**Income**

My mother is getting social grant and my grandfather. No one is working at home.

**Need**

I need a bursary to further my studies after grade 12, So that I can be able to take care of my mother in future.

**Participant no3: 21 years' male- mother MHCU since he was born**

Sometimes there are problems at home.

Sometimes my mother has a problem of taking treatment from the hospital.

When she missed the treatment she becomes shivering.

My mother is always demanding everything from me.

When I am trying to read I have problem in coping because I am thinking about situation at home.

When there are some arguments at home I play gospel and sometimes I go to church if it is time to church.

Because I am the first born my mother is always demanding everything from me. Such as reminding him to take medication and taking him to the clinic.

When my mother is sick I am the one who take care of her.

One day when I am sitting alone thinking about my mother and the whole situation at home tears started running from my eyes.

I started school late because of my mother's mental illness.

If I can fail this year, I am dropping out from the school because nobody is taking care about me, and I am struggling to get things for the school.

**Coping strategies**

I have accepted the situation

Playing gospel music

I want to study hard in order to come and take care of my mother

**Income**

My brother and my sister are working.

My mother is getting social grant and getting money from insurance.

**Needs**



I want someone who can sit and talk to me and advise me about this situation.

**Participants no 4: 22 years' male- uncle MHCU since he was born**

I have experienced both challenging and unchallenging things.

Unchallenging things- When I just woke up the other day a person who is mentally ill is just different from other days and do some strange things.

The other day I do not know if my uncle was drunk or smoked harmful things, he just started doing strange things, painting walls inappropriate way, shouting and singing on the street, wearing goggles and skirt, abusing language and swearing other people.

One day I was from the school, he was sent to the clinic, on the way to the clinic, he ran away and undress himself on the street while running. I was disturbed when I was doing matric because my uncle was singing and shouting day and night without sleeping.

When he started he was chasing people at home. I remember one day he was painting the spade.

Sometimes when I was growing up I was laughing the things that my uncle was doing.

Fortunately, my grandmother explained to me that long time ago my uncle became ill and I must not be surprised.

My grandmother told me that my uncle was abusing marijuana while he was still at high school.

I am not sure if marijuana can cause mental illness.

The sickness comes and goes.

My grandmother and my other uncle managed to take my uncle to the hospital for a week and he came back fine.

Unchallenging things- If my uncle is better he is a cool person. He does not trouble other people.

He laughs with people. He talks nicely with others. He is always at home because he has no longer having friends.

### **Coping strategies**

Do not provoke a mentally ill person.

Do not switch off the fire by petrol.

I talk with my uncle nicely

I am ignoring him when he is doing strange things.

### **Support**

My grandmother and my other uncle are giving us support

My grandmother is the one who is supervising my uncles' treatment and she is always looking after him and she is unable to visit.

### **Income**

My uncle and my grandmother are getting social grant. My other uncle is working

We managed to meet the basic needs.

### **Needs**

We need someone to remind my uncle to take medication

### **Participant no 5: 23 years female- mother MHCU since she was born**

My mother is a lovely person except when she is sick.

When my mother is sick she breaks windows and every property at home. Sometimes when I talk to her, she started to fight saying I am disrespecting her.

I have accepted that my mother is mentally ill because it is the will of God. There is nothing I can do. I felt bad at first when realising that my mother is mentally ill.

I failed three times at school. When I was doing grade 3 my mother became sick while I was busy with the examinations.

She was shouting and making a lot of noise and I was unable to study and prepare for the exam. When I was in grade 11 I became pregnant and I gave birth in August and I was approaching examinations and I did not have enough time to prepare. When I am doing grade 12 for the first time the noise and shouting of my mother disturbed me and I failed.

Now I am reading at school because I am not managing to study at home.

My grandfather is the one who is reminding my mother to take medication.

### **Coping strategies**

When my mother is sick I locked myself in the room because she says I am disrespecting her and I am also calling for the police.

### **Support**

Neighbours are giving us support because when my mother is sick she is fighting, the neighbours help us until the police arrived.

### **Income**

I am getting child support grant, my mother is also getting child support grant, and my grandfather is also getting support grant.

### **Needs- None**

### **Participant no 6: 19 years' male- mother is MHCU since he was born**

It hurts me to realise that my mother is mentally ill.

One day when I was in grade 3 three, I was from the school and I found a van parked in front of my home.

My mother was picking up the papers, running around and undressing in public.

She was taken to the hospital and was admitted for five days and came back fine.

I have asked my mother about her behaviour, and she said she was intelligent at school and started to become mentally ill.

I was worried, why my mother was starting to see things and becoming mentally ill.

## **Coping strategies**

I talked with my mother and she said I must not allow her condition to disturb me. She said I am not the first one to be this situation.

In some other families you will find that is only child and mentally ill parent. I am better because I have my brothers, sister and my father. I must be patient.

## **Support**

My brothers, father and sister are giving me support.

## **Income**

My mother and my father are getting social grant, my brothers are working

## **Needs**

What I need is advice about mental illness

## **Participant no 7: 20 years female- brother MHCU since five years ago**

We are living well with my brother.

He is not giving us problems.

We accompany him to the clinic and supervising him to take treatment.

Sometimes he became sick and walking throughout the night and we have to go out and look for him.

Sometimes my mother call him on his cell phone and ask his where about so that we can go and fetch him.

I have left my job, my mother also left her job in order to come and take care of him. My sister also left job.

Sometimes he breaks things at home, beating walls, doors, moving the fridge, wardrobes saying people are strangling him.

When he is doing these things we have to stay with him and guard him. We are supervising him for 24hours.

### **Coping strategies**

I am patient and accepted that my brother is ill.

I know him suffering from Diabetes mellitus and sometimes he is not thinking well.

The church is helping us with rituals (ditaelo).

### **Income**

We are depending on his social grant and child support grant.

### **Needs**

I need a nurse who can visit once a week in the family in order to come and give us information and guidance on how to relieve stress.

### **Participant no 8: 21 years' male – mother MHCU since 2005**

We are running short of a lot of things and motherly love here at home.

I felt bad when I realised that my mother is mentally ill.

She started by undressing.

My father had to stop working in order to come and take care of her.

But now my mother is passed away.

My mother's illness affected me psychologically when I am growing up.

I started smoking in order to relieve stress.

Now my mother is taking treatment and they are making her better.

My stress is now lessened.

I failed at school because I had no time to study.

My mother's illness affected my studies.

I even thought of dropping out from school.

This was also affected my other brothers who also repeated grades at school

### **Coping strategies**

I have accepted because my mother is now taking treatment.

### **Support**

My grandmother is giving us support

### **Income**

We are depending from my mother social grant. My brother is doing some piece jobs.

### **Needs**

We lack things such as food, clothes and school uniform

### **Participant no 9: 22 years' uncle- MHCU since**

My uncle started to become mentally ill when I was doing grade 4.

He started by throwing other people with stones on the street and doing some strange things.

I felt bad because he is my uncle and people were laughing and disrespecting him.

I felt bad because he was the one who was taking care of us. He also started throwing us with stones and we ran to my aunt and stayed there until my other uncle took him to the hospital.

I am the one who is taking care of my uncle, my siblings and my grandmother because she is partially blind. I cook, clean and wash for my uncle.

My uncle is beating and swearing us saying we are taking his money.

He is selling everything at home for gambling. His friends are encouraging him to gamble.

My uncle sold chickens, cell phones and solar.

He is always beating my younger brother who is 18 years.

His SASA card and Identity book is with a woman who is a machonisa (money loaner).

She is taking his money every month. We tried to request her to give us the card and Identity book of my uncle but she refused.

I failed three times at school.

My uncle is taking treatment by himself.

No one is accompanying him to the clinic.

We use to see my uncle's tablets in the toilet.

Different money loaners are used to come here at home looking for their money.

### **Coping strategies**

I am patient, not answering him and keeping quite when he is angry.

Because I am the only one who is looking after them. I am the older one.

### **Support**

No one is giving us support. My other uncle who was giving us support is passed away.

### **Income**

My mother is working. My grandmother and my uncle are getting social grant

### **Need**

I need a social worker to come and visit us every month in order to check if my uncle is buying food and clothes with his money.

### **Participant 10: 22 years female- MHCU since she was born**

It is not right to live with a parent who is mentally ill because she is inpatient. Sometimes she is shouting me.

Sometimes my mother is not taking her treatment.

Sometimes my mother wants to beat me.

### **Coping strategies**

I am not coping because I am always thinking about it when I am at school because my mother swears at me.

I am repeating grade 10. Sometimes I do not have time to study because my mother is shouting, swearing and promise to beat me.

I am not concentrating at school. This is affecting my studies.

### **Support**

My aunt and other family members are giving us support

Income

We are depending on my mother and my uncle's social grant.

### **Needs**

I want my mother to be assisted to take treatment properly and avoid shouting me.